# MORALITY IN ACTION:
# RISKING DEATH AND CARING FOR LIFE IN AMERICAN FOOD ALLERGY WORLDS

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# MORALITY IN ACTION:
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This dissertation investigates the social effects of the food allergy "epidemic" in the contemporary United States, a state of affairs which activists publicize in highly moral terms, based on multi-sited ethnographic research conducted from 2013 to 2016. I argue that the moral framing of this apparent threat to health by mothers, sufferers, and activists is strategic, leveraging gendered obligations to provide care for the young, sick, and disabled, pharmaceutical and food industry approaches to marketing that make moral appeals to customers, and American political sensibilities about who is deserving of accommodations and concern to gain public recognition for food allergy as a life-threatening disease. Situated at the interface of science and technology studies (STS) and medical anthropology, this dissertation brings together risk theory, the anthropology of ethics and morality, STS and anthropological understandings of medical technologies, disability studies, and feminist theory and research on gender and caretaking.

This text brings to light how patients and caretakers balance the risk of harm and death posed by a highly allergic body with the desire to live a "normal" social life, how the pursuit of the "hygienic sublime" to minimize risk intensifies the moral stakes of caretaking and self care work, and what is at stake socially, morally, and financially in positioning food allergy as an easily manageable condition versus a serious disability. Shared experiences, including the use of elaborate hygienic techniques to ensure the safety of foods and environments and reliance on biomedical tools like epinephrine auto-injectors, and a shared fear of death unite adult sufferers

and caretakers of allergic children with other stakeholders to engage in legislative advocacy and public awareness campaigns to ensure the safety of people with food allergies. The resulting food allergy advocacy community is emblematic of the role played by patient advocacy in healthcare today: through complicated alliances with physician-researchers, the highly professionalized patient advocacy industry, and deep-pocketed pharmaceutical companies, food allergy activists seek to make the formerly private and shameful problem of food allergy a matter of shared, public responsibility.

# BIOGRAPHICAL SKETCH

Danya Glabau’s research is located at the intersection of science and technology studies (STS) and anthropology. Her research program to date seeks to understand how the patient experience of chronic illness is shaped by expert biomedical knowledge and discourse. Her dissertation, “Morality in Action: Risking Death and Caring for Life in American Food Allergy Worlds,” examines the moral reasoning of members of the food allergy patient and patient activist community in the United States based on ethnographic fieldwork conducted 2013-2016. Their moral world is influenced by both the practical challenges of living with the disease and the logic of risk and prevention that shapes patient care in contemporary biomedical contexts. She holds a BA in Biological Sciences from Cornell University, an MA in Science and Technology Studies from Cornell University, and a PhD from the Department of Science and Technology Studies (STS) at Cornell University. She is currently Faculty at The Brooklyn Institute for Social Research, Director of Medical Affairs at Intrommune Therapeutics, and Director of Medical Affairs at Allovate Therapeutics.

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## TABLE OF CONTENTS

# LIST OF FIGURES

# CHAPTER 1

# INTRODUCTION: ORIENTING FOOD ALLERGY ADVOCACY AND EXPERIENCE IN THE CONTEMPORARY UNITED STATES

“No Do-Overs With Food Allergies, Only Tragic Endings” screamed the headline of a September 29, 2015 *Huffington Post Parents Blog* post (Mandelbaum 2015). “No Sandwich Is More Important Than a Child’s Life” asserted another from September 23, 2015 (Spohr 2015). On my bookshelf for months, a book called *The Peanut Allergy Epidemic* (Fraser 2011) was hard to ignore, with its disintegrating, blood-red, all-caps spine lettering. In communities where widespread malnutrition and deadly infectious childhood diseases have largely retreated, food allergies have taken their place as a medico-moral *cause célèbre* for parents, medical workers, and medical researchers seeking to ensure the safety of innocent children. The fear has some basis in fact in the United States, if public health statistics are to be believed: somewhere between 5% and 8% of US children have a food allergy (as well as 5% of adults), with about 25% of food allergic children being allergic to peanuts, the most common food allergy (Gupta et al. 2011; Jackson et al. 2013; Sicherer and Sampson 2014). Even social scientists are not immune to the disease’s allure; they have referred to food allergies as an epidemic, a plague, the quintessential “modern malady,” a disease characteristic of civilization (Jackson 2001, 2007; Waggoner 2013). Their mysterious onset (which involves a combination of environmental exposure, heredity, and individual biology), unpredictable development, apparently sudden increase, and potentially deadly effects make them a source of fear for middle class parents worldwide.

This dissertation records my journey into the food allergy world in the United States from 2013 to 2016. It argues that medical care is a deeply moral practice, even when it is carried out under the banner of rational, scientific biomedicine. Questions about what to do to care for someone with food allergies are motivated both by a sense of urgency – an immediate need to act in order to save lives – and aspirational considerations about how one can, or should, live with the condition. Food allergy advocates are engaged in a project of expanding the sphere of responsible caretakers beyond the confines of the nuclear family, enlisting educators, policymakers, and the public to the effort through activism and legislation. Mitigating the risks of food allergies to the allergic individual ought to be a project of communities and societies, in the view of those involved with food allergies, including parents, patients, researchers, and professional advocates. As healthcare in so-called developed countries shifts away from the treatment of infectious disease and toward the management of chronic, "lifestyle" diseases (which are increasingly understood as disorders of the immune system), this style of patient activism and the vision of society it promulgates will become a more prominent fixture in debates about how to care for chronically ill and disabled populations. The goings-on in the food allergy world stand in as a "moral laboratory" (Mattingly 2014b) for the broad social changes that accompany the changing practical and epistemological regimes of biomedicine.

The "food allergy world" or the "food allergy advocacy world," as I call it throughout this dissertation, is a diverse community of individuals, companies, and non-profit organizations who live with or share an interest in safeguarding the lives of people with food allergies. Calling this a "world" is a play on Rapp & Ginsburg's (2012; Ginsberg and Rapp 2013) "disability worlds": communities suffused with care and kinship obligations that coalesce around a shared experience with a chronic disease or disability. Disability worlds are an instance of the broader phenomenon of "social worlds," the sociological idea that collectivities of people work together on common problems or goals using a common set of practices and tools, and in the process make meaning of themselves and their community (Clarke and Star 2007). The food allergy world is largely dominated by people concerned with caring for *children* with food allergies. While children are the public face of this disease, only slightly more than one third of people estimated to have food allergies in the United States – 6 million out of 15 million – are children. Nonetheless, saving children from unnecessary illness and untimely death is the glue that holds together this diverse cast of characters. This began to change somewhat during the course of my research, with allergic adults and parents of college-aged children bringing more attention to the challenges faced by people living independently with food allergies. In this dissertation, I attempt to capture the voices of both parents of food allergic children and their allies *and* the voices of food allergic adults. But because of the makeup of the community, the voices and concerns of parents often dominate my empirical material and by extension significantly shape my analysis.

Three complementary analytic concerns fall under the umbrella of "the moral" as an underlying motif in biomedicine. Concerns about the moral potency of particular medical technologies have been worked out in the STS and anthropology of medicine literatures. To date, life-preserving and reproductive technologies have dominated discussions about the effects of medical technologies on the institutions of society, such as kinship (Cohen 1999; Sharp 2000; Lock 2002) and political economy (Scheper-Hughes 2000, 2001a, b; Fassin 2012). For those living with food allergies, "life-preserving technologies" could be said to include both sophisticated medical devices, like epinephrine auto-injectors, and quite ordinary domestic and industrial techniques of food production. A second component of the moral is the politics and rhetoric of the risk posed by food allergies, since measuring and reducing risk accurately and consistently means, potentially, saving lives. Risk is a potent metric in contemporary politics and medicine because it seems to rationalize a sense of moral precarity – the sense that at any moment something can go wrong, causing injury to limb and life, friends and kin. In food allergy, what are most often stated to be at risk are the lives of vulnerable children. Reducing the risk of allergic reactions in children has effects beyond the present moment, since it is a way to safeguard members of the next generation. Preventing risky allergic reactions is thus a moral project important for social reproduction, with domestic activities like food preparation and motherly caretaking used for mitigating potential harms. The third moral issue at stake is that of caring for people with chronic illness and disability. How best to care for people with physical differences or impairments is often framed as a political issue, an economic issue, or an issue of rights to access the resources needed to live "the good life." This analysis foregrounds the moral obligation to take care of people with chronic medical conditions, as well as the characteristics, expectations, and constraints placed on those who are assumed to be or made into caretakers.

Without a widely available and reliable treatment for the underlying disease, this moral framing helps sufferers and caretakers make sense of the restrictions upon their health and social lives that result from a food allergy diagnosis. Everyday caretaking practices largely take the place of the technological fixes and expert biomedical care that most individuals in biomedical societies expect to find when they receive news of a new ailment. The practices that matter most for food allergic living, such as food preparation and vigilance concerning the safety of young children, are intensified yet still refracted through the ordinary moral order of society. For example, it is largely mothers who are responsible for keeping children safe and happy at mealtime, and mothers and women organize grassroots support networks for fellow caretakers and sufferers. In public settings, disability legislation and case law – legal realms in which the moral imperative to take care are already codified into bureaucratic procedure – are used to enforce the moral demands and social needs of people managing the condition. My analytic framing of food allergy management and advocacy as a moral issue emerges in response to observations like these. Stuck without a cure, the food allergy community seeks to remake society in its own image, mirroring its internal moral logics, to ensure the safety of people with food allergies.

Throughout its history, the concept of “allergy,” first coined in 1906 by Austrian pediatrician Clemens von Pirquet, has contracted and expanded in scope. From an initial meaning of any form of altered reactivity (a definition that included “normal” immune responses to pathogens), it became narrowed to indicate only unusual, individualized reactions to particular eliciting substances, and today has an additional colloquial meaning of extreme dislike or aversion (Jackson 2007). Food allergy has been both emblematic of the concept of allergy and difficult to fully understand using scientific models of allergy and immunity, resulting in widespread neglect of food allergy by what Matthew Smith (2015) calls “mainstream” allergists. Smith defines this group as those allergists who strictly define “allergy” as a condition that is linked to a single biological pathway with characteristic, testable biomarkers, molecules called immunoglobulin E (IgE). Divisions between clinicians and lab scientists (Jackson 2007; Jamieson 2010; Anderson and Mackay 2014) form another key dynamic contributing to the halting nature of progress in the specialty. Caught in the middle of these debates are food allergy sufferers who struggle to make sense of scientific knowledge and recommendations in the context of their own lives (Nairn 2011). As the following chapters will show, patients and caretakers are continually negotiating the status and context of biomedical knowledge as they make decisions about how best to manage with a food allergy diagnosis.

Some scholars have examined how the changing understanding of “allergy” (and related diseases that pivot around sensitivities to substances in the environment, like asthma, sick building syndrome, and multiple chemical sensitivity (MCS)) has been tied up with hopes and reservations about the capacity for modern technology to improve human life (Murphy 2006; Mitman 2007; Raffaetà 2012, 2013). The envirotechnical (Russell et al. 2011; Pritchard 2011) forces that shape everyday life in the 20th and 21st centuries – increased geographical mobility that displace individuals from their “homeland” with great regularity, the ability to separate the “natural” environment from the “culture” of the indoors by means of artificial materials, and innovations in food and materials manufacturing that blur the line between nature-made and manufactured – have apparently given rise to new kinds of diseases. These new diseases are chronic, long lasting, and respond to non-obvious environmental triggers, making it difficult for biomedical science to map new collections of symptoms onto a malfunctioning biological process. They are also difficult to detect using existing tools. To use Michelle Murphy’s (2006) terminology, they fall into “regimes of imperceptibility” (Murphy 2006) where triggers and somatic indicators of felt maladies are both outside the range of detection. Food allergy shares some etiological and symptomatological elements with asthma, sick building syndrome, and allergies to environmental substances, but more importantly, their very existence is similarly difficult to verify by technological means. Environmental illness and allergy present patients, clinicians, scientists, and the casually interested public with a situation where the best tools of biomedical science can fail to reach a conclusion, demanding that patient experience be taken as proof enough of biological dysfunction. The doubt introduced by this state of affairs is a salient feature of life with food allergies for many of my interlocutors.

A third line of inquiry, focused on food allergies specifically, concerns the contemporary life of the allergy concept. One group of sociologists has led the way, mapping out a sociological agenda for studying food allergy that focuses on understanding the complexity that surrounds definitions of the diagnosis (Nettleton et al. 2009, 2010). As these researchers describe, the distinction between "allergy" and "intolerance" is one that remains muddled among members of the public, despite the best efforts of some allergists in the UK. (In my research in the United States, I discovered that many American allergists do not even make this distinction, with some admitting that intolerances may simply be undetectable allergies and others arguing that "intolerance" is not a valid disease category.) Given this complexity, patients sometimes mold the concept of "allergy" to suit their needs, to the chagrin of allergists. Miranda Waggoner's (2013) work rounds out the sociological approach to date. Waggoner examines the rhetorical life of the idea of a "peanut allergy epidemic," concluding that the idea was co-constructed through conversations between actors in the media, expert physicians, publics, and institutions. Waggoner frames this as the formation of a social problem, a story of "how an individual problem becomes a public problem" (54). Rous and Hunt (2004) suggest that the rapidly growing concern about the supposedly epidemic scale of peanut allergy counts as "moral panic". Notably, however, the stereotypical peanut allergy patient – an innocent child – lacks the deviant agency typically considered essential to the genesis of a moral panic (Goode and Ben-Yehuda, 1994). Regardless of the moral status of the peanut allergy "epidemic", this biomedical category has been made into a social problem that has the power to shape the kind and intensity of stigma and intervention upon individuals. My research picks up this thread with its focus on the current, everyday approaches patients and caretakers use to manage food allergy. Public understandings of the disease straddle the line between seeing it as an individual bodily dysfunction and as a public health emergency in need of new legislation, regulation, and preventive measures based on biomedical knowledge.

This introduction lays the groundwork for the methods and four ethnographic chapters that follow. The next three sections lay out three strands of theory that shape my conception of "the moral": the ways in which medical technologies shape the moral sensibilities of individuals living in biomedical societies; the moral reasoning implicit in modern risk logics; and the potential contribution of disability theory to thinking about chronic illness, care, and biomedical interventions. Following those sections, I provide a primer on the immunological basis of food allergy, presented at a level of detail that will enable the reader to be on the same page as expert food allergy patients and caretakers. The introduction ends with an outline of the chapters to follow.

## The Moral World of Food Allergy

This dissertation is in conversation with the growing wave of research on "the moral" in science studies. My work on the topic is especially inspired by a recent flurry of anthropological research and theorizing on moral experience, now a small subdiscipline that goes by the name "anthropology of morality" (Zigon 2008; Lambek 2010; Csordas 2014; Fassin 2014; Laidlaw 2010, 2014; Zigon and Throop 2014). Social theory in this space conceives of "the moral" as another dimension of human social experience, like "the material" or "the social" – a high-level analytic category that can be traced through a variety of social practices, institutions, and logics. In this introduction, I want to indicate some of the key antecedents to my definition of and attitude toward this dimension of human experience. Without the key intellectual gestures made by writers in this new tradition – including pairing Actor-Network Theory (ANT) with classical anthropology as a way to probe the meaning of agency and responsibility (Laidlaw 2010) and theories of narrative with phenomenology as a way to elucidate the moral significance of pivotal moments that arise in everyday life (Mattingly 2014b) – the analysis that follows would be impossible. But my conception of morality also has much in common with scholarship about care work. For example, I turn to feminist scholarship on care and mothering that illuminates the moral significance of care practices among middle-class, white mothers in the United States whose social and cultural context are similar to those mothers I document here (Hewett 2006). The claims that food allergy activists make about the need to change social attitudes about food allergies led me to disability studies because they seem to echo the concerns of disability scholars who situate disability in society rather than in the bodies of people considered to have disabilities. Both disability studies and feminist scholarship on parenting and care work tackle the morally treacherous trade-offs made by mothers, people with disabilities, and caretakers, though without necessarily invoking “the moral,” or virtue ethics, as such. This dissertation brings the confrontations with normative moral orders that these traditions highlight into conversation with social studies (including STS and anthropology) of medicine.

Cheryl Mattingly’s scholarship on the moral dimensions of how black American families provide care – biomedical and otherwise – for disabled children is one significant contributor to my analytic approach to the moral dimensions of biomedicine. Her work is especially instructive because her subject is close to my own: the moral stakes of raising children with disabilities. She draws on neo-Aristotelian virtue ethics, an area of modern philosophy that attempts to clarify what counts as “the good” for human communities and what can or ought to be done to attain it. Mattingly deploys this analytic perspective to understand what motivates the constant striving for “the good life” that her participants live and narrate. Importantly, her participants are mainly poor, black families from southern California in a community where structural racism circumscribed the possibility for social and economic improvement of all children. The additional burden of disability makes raising children to have access to a better life than their parents had a nearly impossible task. Poor, black mothers must work to overcome stereotypes that others apply to them, which oscillate between belittling and impossibly valorizing their efforts to parent well. These stereotypes include statistics about black children that predict a life of low achievement and crime, historical stratifications in wealth and socialization between black and white Americans, and the logistical, institutional, and moral challenges of raising a child with disabilities (2014a). Moral striving is necessary just to survive, never mind to flourish, in Mattingly's ethnographic setting of continued racial oppression (Mattingly 2014b).

I confront a very different set of cultural and institutional constraints among the parents I encountered in my research on food allergies in the United States. These differences make me careful about directly translating Mattingly's virtue ethics approach, as it assumes constant moral striving in the face of oppression and adversity. White middle-class mothers caring for food allergic kids, who form the core of my participants, simply do not have the same moral and social obstacles to overcome as poor black women in the United States. Nor do they seem especially concerned with instilling in their children a moral sensibility that explicitly facilitates upward mobility. Maintenance of social status is typically, and sometimes explicitly, the priority. Indeed, many boast about the moral *superiority* of themselves and their children. To hear them tell it, living with this condition refines the moral compass of their family and child, making them more sensitive and accommodating toward others. Additionally, by and large, they have access to the cultural and educational tools they needed to be able to approach teachers, doctors, and legislators on more equal footing, easing access to resources and accommodations in public and private life. What I see in this community is a negotiation about how to superimpose the medical imperative to *sustain life* on the job of white, middle class parenting (especially mothering) in the United States. Mothers in particular respond to the pressure to be perfect caretakers in the most American of ways: by seeking support via the public confessional technology of blogging and by engaging in political advocacy for social and institutional reforms that more widely distribute responsibility for their allergic kids beyond themselves and their nuclear families.

My analytic conception of “the moral” is also rooted in concern about the practices and meanings of care work. The food allergy world is an interesting site for deliberations about an analytic definition of “the moral” because the specific caretaking practices associated with this condition challenge what is ordinarily thought of as “taking care” of someone with illness. For people with food allergies, “taking care” of oneself or another allergic individual mainly consists of meal planning, grocery shopping, filing forms to ensure accommodations at school and work, and being prepared to intervene upon the cared-for person’s body directly by using epinephrine auto-injectors in moments of crisis. These are not activities that are typically recognized as part of biomedical approach to care but activities that take place primarily in the private sphere of the home – activities that are, significantly, gendered female in American society (Reverby 1990; Gerstel 2000; England 2005).

This arrangement of care is in sharp contrast to the kind of intensive bodily contact that “taking care” entails between lower-level medical workers (such as medical aides) and their patients (Reverby 1990, England 2005) in many Western biomedical contexts or between ill and well relatives in contexts where Western biomedicine becomes entangled with non-Western traditions of healing (Livingston 2005, Farmer 1992). For the middle- to upper-middle-class milieu of the majority of my participants, the circle of caretakers includes not only the person with allergy and their close family, but also public servants such as schoolteachers and coaches, paid caretakers and private school staff, and the providers of goods such as processed foods and restaurant meals. These individuals and organizations are, one way or another, paid for their services, yet the life-or-death stakes of preventing or responding promptly to an allergic emergency seems to add an extra layer of urgency and obligation to their work.

My conception of the moral has also been shaped by the ethnographic literature on medicine and the body at the interface of STS and anthropology. Discussion of the explicitly moral implications of medical care has been most salient in the now extensive literature on the commodification of human organs enabled by the capacity for biomedical doctors to transplant organs from one person to another (Cohen 1999; Sharp 2000; Scheper-Hughes 2000, 2001a, b). By following human organs from their points of origin through the sometimes obscure pathways they travel to their point of use, this cluster of ethnographic work underscores the ability of modern biomedicine to alter common sense ideas about the moral status of the body, especially its equivalence with personhood. The possibility of exchanging human organs raises questions about the moral implications of ending body-preserving treatments and the legal and medical procedure for declaring the "person" dead when the body remains alive (Lock 2002; Sharp 2000). Notably, many of the ethical and legal frameworks governing the exchange and use of human organs emerged on the fly, providing an example of how the material and discursive "lives" of biomedical objects are generative of new configurations of morality and social relations. In food allergy, the epinephrine auto-injector plays an important role in organizing the moral world of the food allergy community and of life with food allergies. Like other biomedical objects, auto-injectors – and the rules and restrictions upon their use – play an important role in structuring relations of care and obligation between human actors. What is done to care for others in the limited context I studied is suggestive of the intangible moral ties that exist more generally between people with chronic illness and those who care for them.

The ultimate goal of my discussion of "the moral" is to try to understand the moral sensibility of my interlocutors in the food allergy community specifically. That is, what are the moral or ethical positions that matter most to my interlocutors? What concrete practices, such as using epinephrine auto-injectors, and cultural scripts, such as the gendering of caretaking, shape the moral environment of food allergy networking and activism? How do these positions together provide a cultural logic that helps individuals decide what is the "right" or "wrong" course of action when faced with a food allergy diagnosis or related health crisis? When is this moral sensibility unchanging and principled, and when can it be adjusted or reconfigured for present circumstances? Importantly, I am not arguing for a particular normative moral code that ought to govern individual responses to their experience of the disease; while there are some broadly accepted positions, there is also variation based on life circumstances. Understanding the "food allergy point of view" offers important lessons for how chronic illness and disability are regarded more broadly in American society, what activists, patients, and caretakers deem the morally correct ways to treat people affected by illness and disability, and what obstacles may exist due to friction between the patient and activist perspective and the normative moral order of modern health care.

## Risk Studies: From Social Control to Everyday Experience

Living with food allergies means feeling as though one lives in a constant state of existential risk: any and every moment could bring an encounter with a food that initiates a sudden, serious onset of illness. While scholars in STS have studied risk as a product of technical practices and a tool for social control, these approaches do not quite capture how risk is experienced by people with, or who care for people with, food allergies. Science studies scholars in anthropology have come closer to providing an account that fits with the experiences of my participants, highlighting the social and economic frameworks that embed risk logics in everyday social practices, including in the practices of medicine. This section lays out some of the previous literature on risk in STS and adjacent fields, setting the stage for an in-depth treatment of how this concept is mobilized in food allergic living that will be presented chapters four and five of this dissertation.

Ulrich Beck's "risk society" theory (1992, 2007) is one starting point for social scientific approaches to understanding the function of risk in human societies. Beck's particular interest is in how risk is distributed throughout society. In contemporary risk society, Beck argues, everyone is at risk of some kind of misfortune, be it economic, environmental, or political. Risk in the "modern" world is global, globalized, and globalizing – a fact, effect, and force shaping how institutions imagine and plan for the future worldwide. However, risk is simultaneously inequitably distributed, with more vulnerable members of society facing more immediate threats from environmental and economic risks.

STS scholars have been influenced by Beck's analysis but typically seek to understand how actors, objects, and interests work in confluence to produce perceptions of riskiness. This sort of actor-network theory (ANT) inspired approach stresses the "constructedness" of the interests involved in making scientific facts (Latour 1983, Callon 1986, Law 1986, Latour 1987). Facts are thus never neutral or "natural," but are defined by the work of a network of actors made up of bureaucracies and institutions, technicians, scientists and engineers, publics, and the "risky" objects themselves. Stephen Hilgartner (1992) has examined in detail how participants in actor-networks work in tandem to produce "risk objects," or "the things that pose hazards, the sources of danger, the entities to which harmful consequences are conceptually attached" (41). Sheila Jasanoff (1990; Jasanoff and Kim 2009) is similarly interested in the bureaucratic processes that construct risks, but she is more concerned with how these processes enact certain models of citizen participation in governing and governance. According to this perspective, risks and risky objects, like facts, do not simply exist out there in the world; rather, risks emerge as knowable, quantifiable objects through concerted effort. In addition, these scholars illustrate how fundamental risk has become to the governing of citizens and the governance of a wide variety of technologies used in modern life.

Historical studies of the insurance enterprise in England and the United States (Ewald 1991, Porter 1996, Garland 2003, Heimer 2003, Jain 2006) represent another genealogy of risk studies, revealing how legal, accounting, and record-keeping techniques were developed to measure and (re)distribute risk within populations. Risk, as it emerged as a technical object from concrete accounting practices, requires "trust in numbers" (Porter 1996) – faith that projections will come to pass in enough measure to justify outlays of time, expertise, and capital in the present to ensure, prepare for, or mitigate the imagined future. Determining risk requires an algorithmic model for projecting futures forward from the present, which is typically generated through the calculation of statistical probabilities based on current and past characteristics of society and the material world. Implicit in this cluster of research is the Foucauldian idea that the functioning of administrative power is enacted by state and private institutions through interventions upon social and biological reproduction (Foucault 1977, 1997). In this reading, risk is a biopolitical apparatus, that is, one that observes, quantifies, and aggregates the fates of individual conceived of as elements of a natural order governed by regular laws, in order to predict and control the future of a society.

The concept of risk also requires a complicated set of epistemological maneuvers to properly align past, present, and future. In his essay “The Politics of Life Itself,” Rose defines risk as "a family of ways of thinking and acting, involving calculations about probable futures in the present followed by interventions into the present in order to control that potential future” (2001, 7). The need to square unknown future scenarios with the possibility of acting in the present is a tricky proposition, as Ben Anderson (2010) points out: “Common to all forms of anticipatory action is a seemingly paradoxical process whereby a future becomes cause and justification for some form of action in the here and now” (2). Anticipation of future disasters is a prime political problem for modern states, one which requires projecting present conditions into the future to make informed guesses about the political and material needs of the future (Gusterson 2008; Anderson 2010). At stake is not only the status of the state *qua* state at a future point in time, but also the status of its citizens, making anticipation both a technical and an ethical problem. It is also an affective problem, as several anthropologists have pointed out (Masco 2008; Adams, Murphy, and Clarke 2009; Massumi 2010), since in order to enact anticipatory plans, individuals must somehow be incited to take action today. How to do that in the absence of a present disaster is a political problem that has been addressed through modeling a particular future scenario based on outcomes observed in other places and at other times (Mahajan 2008) and large-scale disaster simulations (Lakoff 2008; Masco 2010). Anticipating future crises additionally takes on an explicitly moral cast when one considers the perspective of Mary Douglas and Aaron Wildavsky (1982) that modern, technocratic risk management is a modern form of religious rituals to mitigate the effects of moral pollution. Moreover, the modern state’s responsibility to protect its population from harm through the management of risks can be considered its prime responsibility – one might even say the moral justification for its existence (Foucault 2007).

Thinking risk at the level of patient experience as it is articulated with discourses about the functioning of risk at the state and society level is a topic that is just beginning to be explored. In other words, how does anticipation shape how patients understand their ills in contemporary biomedical societies? Joseph Dumit (2012) and S. Lochlann Jain (2010, 2013) offer some traction for this question by documenting how risks detected in populations are used as justifications for screenings and prophylactic pharmaceutical treatment of individuals in the name of preventive public health. Dumit points out that these risk-detection practices can change a potential patient's identity by encouraging them to incorporate new "facts" about their health into their self-image, a process he calls "objective self-fashioning" (Dumit 1997, 2012). Patients find themselves grappling with the contradictions of "living in prognosis" (Jain 2007) – not necessarily sick yet, or sick today, but with the potential to fall ill at any moment. The growing use of risk and risk factors to describe health status affects socialization patterns, bringing patients (and patients-in-waiting) together in new "biosocial" arrangements (Rabinow 1992). Such motivated communities of ill and soon-to-be-ill (potential, future) patients work together to lobby for the resources they believe are needed to improve management of their shared condition (Epstein 1996, Rabeharisoa and Callon, 2002, Callon and Rabeharisoa 2003, Lock 2006).

One thing this work on living with (biomedical) risk makes clear is that there is slippage between a technical comprehension of "risk" as something countable "out there," in the aggregate, and the apprehension that one is *at risk* in one's own body in particular moments and situations. Rather than dismiss this slippage as proof that the public has been duped, one intended contribution of this dissertation is to explore what it means to experience the world while understanding oneself (or one's loved ones) to be "at risk" of sudden, serious episodes of illness. If we do indeed now live in a "(world) risk society", how does the imbrication of risk discourse with economy, kinship, and social institutions shape how individuals understand the physical ills and accompanying social misfortune? Food allergy is a context ripe for exploring how the subjects of biomedicine interpret risk as an existential fact in their individual lives, since the disease is attaining the status of a social problem informed by biomedical knowledge, yet the risk calculus of who may become ill and when is still mostly fuzzy math.

A "forensic" theory of risk offers some guidance for approaching risk as a lived experience. In her numerous essays on the functions of risk in culture, Mary Douglas identifies it as a key "forensic," or blame-assigning, resource in contemporary Western cultures. Douglas sees risk as a culturally-sanctioned system for assigning blame and taboo no different from the theories of religious "pollution" promulgated by anthropologists in the early to mid 20th century to describe the behaviors of their "primitive" subjects (Douglas and Wildavsky 1982; Douglas 1990, 1992). Douglas's forensic theory of risk allows for a detailed exploration of how individuals draw lines between a seemingly benign cause and a catastrophic effect. In other words, Douglas's work provides traction for thinking about the theories and practices that individuals use to understand the dangers they face in their everyday lives on their own terms, from the ground up.[1] In the world of food allergies in particular, two types of forensic activities are significant: the construction of forensic *theories* about the origins of an individual's food allergies, and forensic *practices* of food purchasing, food preparation, and hygiene in private and public settings.

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[1] Annelise Riles (2011) has studied the bureaucratic practices – the paperwork – that produce financial risk in a Japanese bank. Her orientation toward the practices which produce risks is highly relevant to food allergy, although in this case the practices are predominantly industrial and domestic, rather than financial or bureaucratic. They have a markedly different relationship to power and the vicissitudes of global finance.

For many adults with food allergies and parents of food allergic kids, searching for reasons why they are living with the condition in the first place becomes an extension of living from day to day at risk of serious allergic reactions. They research, formulate, and recombine forensic theories of their food allergy's origins. This impulse to find the root cause of the disease is not unique to people with food allergies; it is well documented throughout the ethnographic literature on other conditions, especially in contexts where biomedicine coexists with other modes of diagnosis and healing (Farmer 1992, Langwick 2011). In the case of food allergies, scientific theories (summarized later in this introduction) point to a combination of inherited susceptibility, the pattern of exposure to allergens *in utero* and in early childhood, and bad luck. Much to the chagrin of patients and their families, these theories lack predictive power: they cannot indicate who will and who will not develop a food allergy until it actually manifests. The forensic fact-finding process thus repeats over and over again with each individual and family who faces a new food allergy diagnosis, while medical science is powerless to slow the growth in the number of people diagnosed.

In addition to searching for the root cause of illness, much time and energy is devoted to identifying, excluding, and blaming the more proximate causes of specific reactions through the use of forensic practices. This is made quite difficult by the logics of safety and purity that underwrite the American food system. As Heather Paxson (2007, 2012) has argued, the food regulatory system prioritizes ontological and bacteriological standards of purity. The regulatory focus is on the exclusion of fraudulent foodstuffs and biological contaminants rather than a careful characterization of the properties of the final product. These logics – and the safety practices they then give rise to – are not sufficient for allowing people with food allergies to eat safely. As a result, food allergic people and their allies have turned into expert detectives and created novel workarounds that make up for this deficit in the regulatory framework governing food production.

The forensic tendency – to identify, verify, and purify foods, spaces, and food preparation equipment – becomes part of everyday life with food allergies. Forensic practices are organized in a way that allows people managing food allergies to pursue what I call the "hygienic sublime" (inspired by Nye's (1994) "American technological sublime"): living in environments that are maximally allergen-free. This pursuit is often enacted through the consumption of aspirational consumer goods to create an image of a well-run middle-class home. For families with allergic children, it is said to be done in the service of enacting social normalcy for their children, which depends on biological normalcy or the access to resources (such as special foods and cleaning regimens) that allow them to mimic normalcy. The forensic approach to reducing food allergy risk in food production is in service to the general moral codes of the food allergy world – the same moral codes which also motivate political and social advocacy. As a result, the private forensic work of food allergy parents is increasingly being inscribed in public advocacy and legislation. These strategies coexist in the project of making life safe for people with food allergies and produce new configurations of risk management not only at the level of individuals and families, but also at the levels of local school communities, workplaces, states, and the nation.

## Disability Studies and the Study of Illness

Food allergy is a peculiar disease because people with this diagnosis do not fit easily into the category of "the ill" or "the sick."[2] Feeling "ill" due to food allergies is episodic and dependent

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[2] Major milestones in the elaboration of the category of "the ill" or "illness" in social theory include Canguilhem's (1978) *The Normal and the Pathological*, Parsons's (1951) "sick role," Goffman's (1961) "moral career" of a mental patient, Zola's (1972) formulation of the "medicalizing" of ordinary problems into objects of biomedical concern, and Conrad's (1992) critique of medicalization as a tool of social control. In this genealogy, the person

on a recent, direct encounter with an allergenic food; a patient who manages it rigorously can, in theory, live an entire lifetime with food allergies without ever feeling ill. Yet this is hardly ever the case because it is usually an unanticipated reaction that leads to a diagnosis of food allergies, and after diagnosis accidents do tend to happen. But the hope – the remote possibility – of an illness-free life leads parents and patients to wonder whether "illness" or "disease" is the right way to describe a food allergy diagnosis., The dominant Western ontology of health status – where individuals are considered either "normal" or "pathological" (Canguilhem 1978) – offers little space for understanding a diagnosis which one may live with successfully for a large portion of their life (Livingston 2005). In the disability studies literature, however, scholars have addressed this difficulty of ontology and language, exploring the social and political stakes of bodily integrity and "abnormal" biological activity. Their work defining "disability" as a *collective social* problem, rather than *individual biological* problem, echoes the reasoning about the condition and approach to political advocacy native to the food allergy community.

The interdisciplinary field of disability studies is united by a coherent theoretical perspective on disability, called "the social model of disability." This model is a social constructionist framework that argues that disability, much like illness (Conrad and Barker 2010), is a result of the social environment rather than an inevitable consequence of bodily, psychiatric, or developmental difference (Shakespeare 1996; Shakespeare and Watson 1997; Barnes 2012). Using this framework, disability scholars (often approaching their subject with an eye toward real-world activism as well as scholarship) try to shift understandings of disability and impairment away from a focus on the deficiency of individual bodies toward making

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with a diagnosis is understood to be socially constructed as different/other, separated from normal society, under the control of others, and both in need of help and special privileges – a highly unfortunate and passive portrayal. Moreover, this genealogy is oriented around deconstructing the *category* and *role* of the sick/ill in society rather than offering a grounded examination of the *embodied experience* of going through life so perceived.

interventions in the social environment surrounding individuals with disabling conditions to enable full inclusion in social life. An “affirmation model” of disability is one consequence of this social constructionist perspective that positions disability as non-negative or positive in and of itself. If it is not a problem, then it is also not something to fear, ignore, or marginalize (Swain and French 2000). “No one is ever more than temporarily able-bodied” is a sentiment commonly found in the field that is meant to flip the conversation and drive home the constructed nature of the category “able-bodied” (Breckenridge and Vogler 2001, 349). Breckenridge and Volger further contend that the fact that the inevitability of disability disrupts “entrenched mind-and-body distinctions and further destabilizes the concept of the normal” even more than critical identity studies fields have thus far been able to do. Despite critiques from within the field, to the effect that this traditionally constructionist stance ignores the everyday material realities of bodily life and embodiment (Hughes and Patterson, 1997; Dewsbury et al. 2004), it has long been the field’s major unifying feature and origin story.

Several feminist scholars have written at length about the intersection of the disability studies tradition with other “identity studies,” particularly with feminist scholarship, taking the field in a direction that has much in common with STS approaches used to study identity and illness (Wendell 1989; Morris 1993; Garland-Thomson 2002, 2005). Garland-Thomson’s vision of disability studies is of particular interest. She draws attention to the ways in which bodies and the categories used to describe them are both materially and ideologically shaped by social categories that are themselves historically changeable. This view echoes that of science studies scholar Ian Hacking’s notion of “dynamic nominalism,” whereby “a kind of person came into being at the same time as the kind itself was being invented” (1986, 158). Yet “disability” as a category and the contributions of disability studies scholars remains largely understudied in science studies (one notable exception is the work of Faye Ginsberg and Rayna Rapp [Rapp 1999; Rapp and Ginsberg 2012; Ginsberg and Rapp 2013]). Some disability studies scholars have, in fact, expressed concern about the idea of ethnographers turning their analytic eye on disability, out of a fear that it will once again exoticize people with disabilities, an issue that should certainly be kept in mind as interest in this topic from outside the disability studies community grows (Kasnitz and Shuttleworth 2001). But what disability studies adds to science studies – particularly to "STS proper" – is a way to think about illness experiences in cases where physical or other forms of debility persist but do not preclude participation in social life; a framework which understands disabled experience as necessarily highly contingent (and thus best accessed through ground-level social scientific methods like ethnography); and which, in concert with STS, anthropology, and sociology of medicine, critiques cultural institutions that presume and/or enforce restrictive social categories based on physical, mental, or other features of individuals.

Disability studies also offers analytic traction for analyzing how my informants in the food allergy community make demands for structural changes in society to ensure full, meaningful integration of people with food allergies into American society. Appeals for the social inclusion of people with the condition are often couched in rights-based language of justice and fairness, similar to both classic and more recent work in the disability studies literature (Shakespeare 1996; Barnes 2000; Burchardt 2004; Dewsbury et al. 2004). Through the course of my research, I have come to see the language of civil rights as a stand in for normative moral appeals. The language of rights appeals to a liberal humanist tradition in which all humans – or, historically, all humans recognized as "full" humans – have certain intrinsic properties. By contrast, disability advocacy is premised on modifying social arrangements to take into account the unavoidable difference of human bodies and modes of relating to the work. Rights language sets up two problems for disability studies: first, it sets up a tension between emphasizing sameness and recognizing difference; and second, it begs the question of who counts as a “full” human subject (does the category include children? the elderly? adults with developmental delays?). Rights language problematically assumes that the people in question see themselves as, and can act as, rational, liberal subjects of a modern democratic state, or that someone can rightfully speak for them. Anthropologist Veena Das is acutely concerned with how to talk about disability in a way that does not “locate the subject positions of the disabled firmly within a liberal political regime” (Das and Addlakha 2001, 511). Though American rights discourses have a different genealogy than the Indian context, I am similarly hesitant to use a rights-based framework to make moral claims about inclusion. Taking rights to be an inherent property of certain individuals obscures the ways in which certain classes of people are constructed to be rights-worthy, worthy of protection, or fit to be ignored. It also presumes universal access to political inclusion when in fact, as some of the chapters that follow will show, class, education, access to capital, and interpersonal networks significantly shape who has social and political representation. My dissertation thus offers a challenge both to food allergy advocates and to disability studies scholars: to more thoughtfully account for the work that rights-based demands about social recognition and provisions of care does, including the domestic labor and other women’s work that it covers up.

Feminist scholarship is helpful here because it reminds us to think about the gender and power dimensions that influence who cares, who is cared for, and who is considered worth caring for (England 2005, Pugh 2011). Power relations in society, feminists remind us, are often organized following essentialist assumptions about gender, age, race, ability, class, and other elements of the life course. For care workers – including parents of children with disabilities – this moral dimension implicitly justifies low wages, personal sacrifices, social stigma, and poor living and working conditions (Abel and Nelson 1990; Reverby 1990; Gerstel 2000; Mattingly 2014a). These are moral questions, and they are questions that remain salient in the lives of people with chronic illness and disabilities. There is a danger that my dissertation reinforces these harmful patterns of sociality, focused as it is in many sections on the views of mothers and their experience with raising food allergic children. At this point in the project, I am constrained by my ethnographic material to make this a recurring theme in my ethnography. I do hope that by voicing the fact that there *is* a moral commitment to go above and beyond in protecting *children* specifically, I can usefully point out the differential worthiness attached to certain kinds of disability or certain categories of the afflicted.

Adults and families without allergic children have often been sidelined, both rhetorically and socially, in the food allergy world. Parents tend to spin this state of affairs in a positive way by arguing that protecting children is the first step in a broader campaign to increase education, social support, and medico-scientific knowhow to make life easier for *everyone* with food allergies. But many of the parents who have played a major role in food allergy advocacy are now realizing that allergic children eventually grow into allergic adults as their own children enter high school and college. A shift in the engines of food allergy activism – from an exclusive focus on children to a more inclusive focus that includes adult sufferers – can already be seen at the non-profit organizations that give voice to parental concerns. The transition from childhood to adulthood is now supported by new committees and training programs for college food service and teaching staff to help them accommodate young adults with food allergies. Only time will tell if the community can deliver on these promises, or if children remain at the moral and practical center of food allergy activism.

At stake in this study of food allergy activism is how to find a way out of deeply entrenched ways of thinking about care, caretakers, and people with disabilities. Care work is work most often done on the margins of economic viability, and by women, whose time and effort is undervalued compared to that of men in American society (Gerstel 2000, England 2005). At the same time, these women's wards – especially those who happen to be white, middle-class children – are considered *most* valuable, worthy of any sacrifice. Food allergy mothers appeal to the public with images and stories about their innocent children, reinforcing these stereotypes about who is deserving of moral consideration. However, the ultimate goal of such advocacy projects is to hold others in society – health care workers, teachers, community members, drug companies, and insurance companies – accountable for the well being of children with food allergies to share the burden of care and reduce the pressure placed upon mothers and nuclear families. This contradiction at the core of how Americans approach care for the sick and vulnerable is a characteristic feature of the food allergy world.

## A Food Allergy Primer

Some key "facts" about allergy warrant a brief introduction. For both lay and scientific members of the food allergy community, scientific models are understood to define what the disease "is," and in turn to shape ideas about what ought to be done about it. They share knowledge about sophisticated models of how allergic reactions are triggered and progress, which biomarkers indicate an individual's likely allergies, and the etiology of the disease. To date, though, none of these theories has produced a reliably effective, permanent treatment with an acceptably low risk of severe side effects. Dietary modifications and sophisticated hygienic routines are thus the only "treatments" that can prevent reactions, while epinephrine (adrenaline) is used only as an emergency medication to stop reactions already in progress. This background on the biomedical understanding of food allergy will help the reader follow later discussions about the use of epinephrine, the experience of food allergy diagnosis and follow-up dietary management, and the risks posed by unexpected allergic reactions to foods.

According to biomedical science, food allergy is just one manifestation of immune system hypersensitivity to ordinary environmental substances. "Hypersensitivity" is a general term for the immune system's exaggerated response to a substance that is not intrinsically harmful to "normal" human bodies. In this cluster of diseases, symptoms arise from the immune response to a substance, not from any intrinsic property of the triggering material. A "true" food allergy is typically defined as a particular immunopathophysiological (literally, "immune system-disease-body process") state that is accompanied by one or several of a number of typical symptoms (Sicherer and Sampson 2010). The most common symptoms of a severe, systemic allergic reaction to food, called "anaphylaxis," include vomiting, abdominal cramping, diarrhea, hives, flushing/redness, faintness, swelling of the mouth, lips and face, and swelling of the airways, leading to hoarseness or difficulty breathing (Centers for Disease Control and Prevention 2013). Brain damage or death can result from airway obstruction caused by swelling of the throat, mouth, or lung tissue. Symptoms typically begin within minutes to two hours after allergen exposure, but in up to 20% of cases of anaphylaxis, they recur in a second wave or "phase" four to six hours after the reaction initially begins (Burks et al. 2012). In the clinical training and clinical practice that I observed during my research, anaphylaxis was most readily diagnosed when more than one body system was involved, though references to this benchmark are difficult to find in the published literature. Somewhere between 50 and 91 percent of cases of anaphylaxis are caused by drug allergies, but food allergies are also a significant trigger (Simons et al. 2013).

These symptoms of anaphylaxis are explained as being the outward sign that the body is responding vigorously to something it perceives to be a dangerous foreign substance through an immunoglobulin E (IgE) mediated immunological response pathway. This model of allergy begins the first time an allergen enters the body when pollen particles are inhaled or a food is ingested. The substance is not initially "recognized" as a dangerous element by the immune system. However, for reasons that are not entirely understood, in some individuals the immune system responds to the introduction of new, "foreign" proteins to the skin, mucosal membranes (like the inside of the sinus cavity), mouth, and gut as though they are pathogens (Sicherer and Sampson 2010). Upon early exposures to the food (or other substance, such as pollen or animal dander), the immune system "learns" to recognize proteins as invaders. T cells, the front line cells that spot foreign materials and set off all kinds of immune responses, recognize the invading protein and kick B cells into action. B cells, which play important roles in mediating immune responses and preparing the body for future responses, including those to allergens, viruses, and bacteria, begin to produce specific IgE – Y-shaped particles with one end that conforms to the shape of the protein that the immune system is learning to recognize – that can bind to the foreign material. When the material enters the body subsequently, the specific IgE binds to those molecules on one end and to mast cells and basophils on the other. Mast cells and basophils release materials (degranulate) that stimulate inflammation and attract other immune system components to repel and destroy the threatening substance. Once mast cell degranulation occurs, clinical signs of the allergic reaction can be observed (Lieberman and Chehade 2013).

The IgE-mediated pathway is the only one recognized by mainstream allergists as corresponding to a “true” allergy. Similar symptoms may occur due to other kinds of immunological misfiring or dysfunction, but if they do not match the temporal or systemic character of an IgE-mediated allergy as observed in real life or in diagnostic testing, they are typically believed to arise from a different biochemical pathway and the patient is assigned a different diagnostic category. For that reason, similar kinds of gastrointestinal distress that do *not* result in positive tests for specific IgE to a triggering food are diagnosed as another kind of disease – possibly celiac disease, food-protein induced enterocolitis syndrome (FPIES), mast cell activation syndrome (MCAS), eosinophilic esophagitis (EoE), or idiopathic (literally, “unknown cause-disease”) anaphylaxis (Sicherer and Sampson 2010, Burks et al. 2012). However, *any* set of symptoms resulting from the IgE-mediate pathway count as an “allergy.” Thus, immune responses to inhaled substances like animal dander or pollen that produce different sets of symptoms (primarily respiratory and rarely life-threatening) are still called an “allergy” because they produce similar symptoms and biomarkers, pointing to the same pathophysiology.

The clinical use of asthma medications serves as a good example of how shared immunopathophysiology guides treatment in standard allergy care. The subset of asthma patients who suffer from so-called “allergic asthma” can be treated by a combination of medications that target the IgE-mediated disease pathway and drugs more specifically indicated for the treatment of asthma.  These include combinations of allergy treatments, including antihistamines (which prevent the body from responding to histamine, a late-stage product of an IgE-mediated reaction) and steroids (which reduce inflammation caused by histamines and other mediators in a number of inflammatory pathways, including the IgE pathway), with asthma medications that prevent mast cells from degranulating (such as monteleukast, marketed by Merck as Singulair) and cutting edge injectable drugs that are intended to reduce the immune system's overall response to IgE (omalizumab, Genentech and Novartis's Xolair) (Muraro et al. 2014; Nadeau et al. 2011). Asthma drugs are, conversely, sometimes used to treat diseases with a suspected allergic pathology as well. Monteleukast in particular has been tested in clinical trials as a way to prevent the development of eosinophilic esophagitis, an immune system disorder that is not an IgE-mediated allergy, in patients being treated for food allergy (Takahashi et al. 2014).

A patient's allergic status is determined through a combination of three kinds of information: qualitative, historical data about past reactions that a patient reports to their physician; semi-quantitative skin prick testing (SPT) in which a device is used to gently scratch and introduce purified allergen extracts onto the patient's skin; and quantitative blood serum immunoassays, most often conducted in commercial diagnostic labs. However, SPT and immunoassays correlate poorly with the severity of reactions resulting from consumption of a food (Sicherer and Sampson 2010; Burks et al. 2012). "Positive" blood test results in particular have poor predictive value, indicating allergic sensitivity at the molecular level that is frequently not corroborated by observable allergy symptoms (Perry, Matsui et al. 2004).

Despite their technological novelty, quantitative immunoassays are thought to correlate less reliably with observable symptoms than SPT. The sharp growth in serum food allergy diagnostics since the introduction of the newest generation of tests in 2011 is concerning because many patients restrict their diets following a "positive" diagnosis, often against medical advice. Restricting one's diet by eliminating a food based on a blood test when there are no symptoms puts patients at risk of nutritional deficiencies without meaningfully reducing their of risk allergic symptoms. Skin prick tests correlate reasonably well with the *likelihood* of future reactions, though they fail at accurately predicting the *severity* of those reactions. Reactions to potential allergens introduced via the patient’s skin can be modulated by an individual’s use of over-the-counter antihistamine medications and health status at the time of testing, introducing additional noise to the results of SPT (Burks et al. 2012, Perry, Matsui et al. 2004).

Regardless of these problems, SPT and serum immunoassays are currently the diagnostic standard of care and are used routinely by physicians. Because of their shortcomings, physicians are instructed *not* to rely solely on diagnostic tests to make a food allergy diagnosis, but to also take into account the patient’s particular self-reported history of reactions (Sicherer and Sampson 2010). The patient’s subjective experience thus remains integral to the food allergy diagnosis. Foods which can be linked to reactions historically *and* by a blood or skin test are considered certain allergens, as are foods that yield a negative test but are definitively linked to reactions by the patient’s history. Foods that only yield a positive blood test are considered by physicians to be safe unless or until symptoms develop as well, though, out of an abundance of caution, many patients will avoid all “allergens” as diagnosed by blood or skin tests.

The fact that there is no reliable way at present to predict whether an individual will develop a food allergy, no incontrovertible trigger or sign that can be quantitatively tested which would indicate that disease is developing before a person has had their first reaction, makes food allergy an odd duck in modern medicine. The diagnostic process for the disease is in stark contrast to many other areas of medicine, particularly those concerning other chronic conditions like cancer and high blood pressure, something medical anthropologists have commented on at length in recent years (Jain 2013, Dumit 2012). Food allergy diagnostics still stand outside the risk-reduction paradigm of modern medicine.

The lack of predictive power of current diagnostics, and consequently their underlying etiological theories, is particularly troubling to physicians, parents, and activists given the recent and ongoing increase in rates of food allergies. According to a 2013 US National Center for Health Statistics report, often cited in the allergy literature, the rate of food allergies among US children increased from 3.4% in the 1997-1999 National Health Interview Survey to 5.1% in the 2009-2011 survey (Jackson et al. 2013). They also reported detectable differences in prevalence by income level, with higher rates among higher-income families, and by racial category, with Hispanic children reporting the lowest levels of respiratory allergy, food allergy, and asthma. Similar numbers have been reported by European researchers (Nwaru et al. 2014). Much to the dismay of clinicians, policy makers, and parents and sufferers, etiological theories to date fail to explain the origins of these differences as well as the rising prevalence. Nonetheless, these ideas circulate widely within the food allergy community because they offer some, if imperfect, ways to understand the misfortune of life with the disease.

The “hygiene hypothesis” is the most popular etiological theory of allergy. It suggests that modern biomedical interventions and hygienic practices which reduce a young child’s exposure to pathogens (particularly common childhood viruses, including measles) leaves the maturing human immune system with too little stimulation. In individuals with an inherited disposition, the understimulated immune system redirects its efforts toward recognizing ordinary substances like food proteins, pollen, and animal dander as dangerous pathogenic invaders. As the susceptible infant’s immune system matures, it tends toward heightened reactivity to substances in the environment, including foods (Strachan 1989, Strachan 2000, Brooke, Pearce, and Douwes 2013). Upon subsequent exposures, this model suggests, the immune system attacks rather than tolerates these materials, producing allergy symptoms.

Recent research has taken the idea that early life exposure to microbes modulates immunity and the risk of developing allergy in a new direction. New studies suggests that the development of an individual’s microbiome – microorganisms living in and upon the human body with benign or beneficial effects upon their human hosts – also plays a key role in mediating the sensitization process, along with other key metabolic and immune functions (Brooke et al. 2013; Berin and Sampson 2014; Penders et al. 2014; Liu 2015). Research that I saw presented at a 2014 scientific conference, for example, points to early life exposure to bacteria that produce signaling molecules related to digestive processes as a predictor of reduced rate of multiple allergic diseases (Lynch et al. 2014). The same study noted, counterintuitively, that exposure to common environmental allergens, including cat dander, dust mites, and cockroaches, protected against disease, further complicating the interactions between young immune systems and biological material in their world. Their findings, the authors explain, suggest that “the general tenets of the ‘Hygiene Hypothesis’ are applicable” beyond pathogenic viruses. Without these beneficial microorganisms, food particles can more easily leak out of the gut and into the bloodstream. There, the immune system is more likely to tag food proteins as dangerous invaders, setting the individual up for lifelong allergies (Sicherer and Sampson, 2010). The great irony of the “hygiene hypothesis” and subsequent “microbiome hypothesis” (Liu 2015) is that the environment seems to be both a first cause of allergic disease and a source of immune system resilience.

Another set of theories assigns responsibility to the mother’s pre- and post-natal behaviors. These “mother-blame” (Blum 2007) theories are troubling to many of my participants, clinicians and parent-activists alike. The first of these theories linked maternal diet to the development of food allergies in childhood. In the early 2000s, the theory that maternal consumption of commonly allergenic foods during pregnancy and breastfeeding could sensitize their child to those foods was widely accepted in American medicine. For that reason, the

American Academy of Pediatrics (2000) recommended that mothers avoid common food allergens while breastfeeding and peanuts even during pregnancy (Lack 2012). But, in 2008, the American Academy of Pediatrics walked back its position on the issue. Manipulating maternal diet during pregnancy and breastfeeding was no longer recommended as a food allergy prevention strategy (Greer et al. 2008). There is also controversial associative evidence for a link between food allergies and breast-feeding. In theory, immune system signaling molecules in breast milk could reduce the risk of a child developing food allergies, analogous to the transmission of immunity to pathogens via breast milk. However, as with allergy diagnostics and other etiological theories, the *predictive* value of this research is small, and changing the breastfeeding woman's diet to prevent the development of food allergies is no longer recommended (Lack 2012). In allergy as in many areas of medicine, it is difficult to translate population-level trends into recommendations for individual action.

The preceding pages have briefly summarized current scientific knowledge about food allergies without extensively unpacking the conditions of its production, in order to provide some useful background for the ethnographic material that is to come. The actions activists take are shaped by their shared understanding of certain "facts" about immunity, the human body, and the pathophysiology of food allergy. Regardless of whether these facts will endure as "truth" or will be replaced by some future, unforeseen scientific paradigm (Kuhn 1962), they are what drive action in the present. The task of unraveling the deeper history of allergy science, including the power and credibility struggles within the field, has already been tackled by historians Carla Keirns (2003), Gregg Mitman (2007), Mark Jackson (2007), and Matthew Smith (2015). New ethnographic work on recent controversies in food allergy research is being undertaken by STS scholar and PhD student Stephanie Nairn at McGill University, a topic she began investigating in a Master's thesis (Nairn 2011). Given the complementary efforts of these scholars, here I focused on the generally accepted knowledge produced through these struggles, which shapes the actions of my particular, primarily non-scientist, ethnographic interlocutors.

In sum, food allergy remains largely uncertain for people living with the condition, those advocating on their behalf, *and* the physicians who treat and advise them. The etiological and mechanistic models summarized in this section are among the most widely accepted, however, and patients and physicians allow them the status of fact. They shape medical testing regimens, approaches to treatment, and, as will be discussed at length in the chapters that follow, the social and legal responses to the global food allergy "epidemic." Importantly, they constitute one kind of conversation about responsibility among a multitude of such debates that shape the everyday lives of people with food allergies in important and intimate ways.

### Map of the Dissertation

The dissertation consists of this introduction, a short chapter on methods, four ethnographic chapters, and a conclusion. Themes of risk, care, disability, chronic illness, the circulation of biomedical objects, and "the moral" introduced in this chapter run throughout the ethnographic chapters. Empirically, each chapter is organized around a significant pillar of the food allergy experience: emergency responses to the condition, the everyday techniques used to manage the risk of reactions, what it takes to make food "safe" for allergic people, and the advocacy project of expanding responsibility for people with food allergies.

Chapter Two is discusses the research process and methodology, situating this project as being in conversation with scholars in both STS and anthropology. As is often the case with ethnographic research, the focus of the project changed significantly in the early stages of research; the methods used to embed myself in communities of interest and collect data changed accordingly. The dispersed character of the communities I observed – nationally dispersed food allergy advocates, globally dispersed allergy experts, food commodity chains, and pharmaceutical companies – required a multi-sited approach (Marcus 1995) informed by actor-network theory (Latour 1983, Callon 1986, Law 1986, Latour 1987). Chapter Two summarizes some of the precedents for multi-sited ethnography, situates this project in that tradition, and provides a brief summary of how this project actually came to be multi-sited and how this influenced the evidence upon which this analysis is based.

Chapter Three, "The Moral Life of Epinephrine," follows the trail of epinephrine auto-injectors on some of their material and discursive journeys within the food allergy community. Epinephrine auto-injectors are medication-delivering devices that allow people to easily administer epinephrine to themselves or others in order to stop severe allergic reactions. While this technology is commonplace, eight months of ethnographic fieldwork in allergy clinics, patient support groups, and food allergy advocacy communities in the United States revealed that the moral significance of auto-injectors is a complicated matter. My research of following the use of and talk about these devices foregrounds the moral stakes of living with food allergies. As arbiters of life and death in emergency situations, auto-injectors shape how allergic individuals and their advocates prepare for catastrophic illness, as well as how they relate to one another through teaching others how to use this device. This chapter brings together scholarship on anticipation, the commodification of medical objects, and morality and ethics in anthropology to sketch a picture of the "moral life" of epinephrine auto-injectors in the treatment of food allergies.

Chapter Four, "Personalizing Risk in Food Allergy Worlds," assembles ethnographic material from people living with food allergies to juxtapose the everyday experience of living "at risk” of a severe allergic reaction with the attempt to answer the question, “why am *I* allergic?” I focus on the interplay between living with food allergy and interpreting biomedical knowledge about the etiology of food allergies. The evaluation and management of the risk of bodily harm is central to life in allergy worlds, whether one has allergies oneself or cares for someone else who does. Adults with food allergies know the risks posed by this condition in an embodied way, and it guides the choices they make about medical care, environmental exposures, and food consumption. Those choices are often at odds with biomedical advice. By contrast, when parents witness their children living through allergic crises, they often hew more closely to the rules in order to protect them. Their narratives justify an alternative epistemology of risk to that proffered by allergy experts. Reflections from food allergic adults and parents of allergic kids also offer an alternative understanding of the temporality of risk: a phenomenon that happens in the present and, by way of individual memory and history, through reference to the past rather than a forward-looking and anticipatory orientation.

The fifth chapter, “The Hygienic Sublime: Making Food Safe for People with Food Allergies,” examines how people living with food allergies and allergy-aware food industry allies make food safe for allergic individuals. On the surface, the binary categories of “safe” and “unsafe,” “pure” and impure,” appear simply to describe the (potential) material properties of foods. However, these categories are also imbued with moral significance. Since eating an impure food product or trusting the wrong food manufacturer has the potential to lead to serious illness or death, policing food preparation is often seen as the front line for warding off death in the food allergy community. This chapter explores the steps taken by food manufacturers, allergy-aware restaurateurs, and home cooks to ensure food allergic individuals have access to "safe food." At stake is a belief in the power of technology and savvy consumerism to make the world appropriately hygienic, and thus safe, for living with food allergies.

Chapter Six, "Advocacy, Disability, and the Law: Redistributing Responsibility for Food Allergy Care," examines how responsibility for caring for people (especially children) with food allergies is enacted in the legislative realm via stock epinephrine bills. Stock epinephrine laws allow or require (depending on the statute) that epinephrine auto-injectors be made available in public spaces to be used to treat someone having a severe allergic reaction. The work of mother-advocates initially focused on bills permitting or mandating stock epinephrine in schools, but more recently advocates and organizations have begun backing "entity" bills, which allow a wider variety of entities (such as summer camps, shopping malls, and restaurants) to keep stock epinephrine. Careful analysis of their advocacy work reveals that stock epinephrine bills are conceived of as a tool for changing how society regards people with food allergies, as much as they are a practical resource for ensuring their safety. In doing so, advocates treat food allergies as a disability that can be made less disabling through appropriate social action, rather than a disabling disease that is solely the individual's problem to deal with. A close examination of a handful of "moral laboratories" (Mattingly 2014b) in which these resources are mobilized will illuminate the ideas about living a "good life" as part of a responsible community that underwrite the activities of food allergy advocates.

Food allergy is a disease that is difficult to understand and manage in the context of modern biomedical science and healthcare delivery systems. Food allergy advocates face an uphill battle to gain recognition for the disease from friends, family, and institutions and the legal protections they deem necessary to live safely. Drawing on the moral potency of the power of epinephrine, the hygienic sublime, and the special moral status of children form the foundations of their claims. In making these claims, traditional gender norms and uneasy alliances with pharmaceutical industry actors are created and reinforced. The story of the food allergy world is a story of making a disease real, of making a trend into an epidemic, and of negotiating how care *ought* to be provided to those in society deemed ill and vulnerable. In all these ways, it is paradigmatic of the issues facing healthcare delivery and illness communities in the United States today.

# CHAPTER 2

# POSITIONING ETHNOGRAPHIC METHODS IN SCIENCE STUDIES

Experience is the basic epistemological orientation of the ethnographic researcher. Firsthand experience of social life provides the raw material for the “thick descriptions” of actors, events, and communities (Geertz, 1973), which is the basis for extracting insights about human societies. Yet the growing attention paid to science and technology within anthropology and at the interface of anthropology and STS has eroded traditional conceptions about what ethnographic immersion can, or ought to, be. This chapter lays out how some of the methodological opportunities and challenges posed by studying a geographically scattered community bound together by shared interest in a technoscientific idea, the biomedical category of a kind of bodily dysfunction called “food allergy.” These notable features of the study at hand are consequences of the intensely networked and physically distributed professional practices of modern biomedicine and the information technology infrastructures that shape social life in the 21st century. This chapter will begin with a narrative of the research process, to be followed by a discussion of several key concepts in STS and anthropology that inform ethnography in science studies. This will be followed by a brief discussion of the link between *doing* and *writing* ethnography, and how the translation from experience to page proceeded.

## The Research: Positioning Myself in an Evolving Ethnographic Project

My ethnographic research was sparked by my own encounter with the allergy specialty in 2009 when I sought diagnosis and treatment for my own potential food allergies from a local allergist in Ithaca, NY. While food allergy blood test results were negative, my “history” – the narrative I told the doctor about episodes of illness and the meals that preceded them – strongly supported a diagnosis. Additionally, an extensive panel of skin prick tests revealed sensitivities to many common environmental allergens, including animal dander, tree and grass pollen, mold spores, and dust mites. As a patient with some basic knowledge of human biology and how things are typically done in medicine, I was puzzled by the uncertainty of the diagnosis, by the odd combination of blood tests and skin prick tests that intentionally provoked my body to react, and by physicians' faith in my reported symptoms. It made me wonder if anyone really knew what was going on inside my allergic body.

It was not until the fall of 2013 that I began to examine the community of allergy doctors, researchers, and advocates who are key players in my ethnographic research. I was still motivated by my earlier puzzlement at the diagnostic process. I deepened and changed my engagement with this world following Cornell University IRB approval to shadow allergists and to conduct a series of open-ended, qualitative interviews with health care workers specializing in treating allergy, food allergy activists, allergy sufferers, and parents of allergic children.

My initial focus was broad: I was looking at all allergies, both food and environmental, in order to better understand the patient experience of a disease which is not spectacular enough to have attracted much attention from social scientists. Questions about the embodied experience of environmentally-induced illness and the shifting ontological borders of the category of allergy dominated my thinking. To investigate these questions, I conducted several open-ended, qualitative, 30 to 60 minute interviews in person and by phone with allergists and food allergy support group leaders and members in a large metropolis in the northeastern United States. I also began shadowing one willing ENT-trained (ear, nose, and throat, or otolaryngology[3]) allergist in

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[3] Otolaryngology is a surgical specialty, that is, their training consists of medical school but a surgery-based residence. Once in practice, most see a large number of patients in-office, with a day or two a week devoted to septum surgeries, tonsillectomies, and sometimes reconstructive or cosmetic procedures. ENT allergists are treated with suspicion by "mainstream" or "general" allergists, who are trained in the medical model. As surgeons, they are believed to treat first and think later by their medical counterparts. They are also thought to be more willing to use untested, "experimental" treatments. In my experience, however, it is more the case that they are busy creating their

his office at a teaching hospital in the city to try to absorb as much as I could about the medical science and clinical treatment of allergy. In the spirit of grounded theory (Glaser and Strauss 1967), I allowed my analytic concerns to develop based on what I found in my early interactions with participants.

It quickly became evident that food allergies are the locus of passion, worry, research money, and activity in the contemporary United States. It also became clear that participants wanted to talk about responsibility, blame, and risk more than anything else – certainly more than they wanted to talk about the historically controversial limits of the category of "allergy,"[4] one of my initial talking points. They raised questions such as: Who was to blame when a child because ill from food allergies? Who could be considered responsible enough to care for a child with food allergies? Could training in technical skills – specifically, the use of an epinephrine auto-injector – make a formerly incapable caretaker trustworthy? What legal frameworks were in place to determine and mitigate the risk of contaminating one food product with traces of unannounced ingredients? Who or what could ultimately be blamed for the global "food allergy epidemic"? In light of the passion and persistence with which these problems came up in early interviews, I shifted the trajectory of my project to focus on what my participants were signaling to me to be the important issues.

Shifting the focus of my project meant that my research suddenly had two prongs: one focused on shadowing two allergists with whom I had already connected who treated a mix of

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own evidence in their own societies and journals, since marquee general allergy journals tend not to publish studies testing ENT allergy procedures.

[4] Smith (2015) has discussed the historical controversy concerning the diagnosis of "allergy." Since the term was coined in 1906, "orthodox" allergists closely allied with immunology have employed a narrow, restricted definition of allergy as an immediate, IgE-mediated reaction to a food or environmental substance. Food allergists, by contrast, use a broader definition of allergy that encompasses a range of vague, chronic complaints that tend to improve with changes to the diet. This controversy persists, though today food allergists have joined the mainstream of the allergy and immunology medical specialty; the modern outliers, growing in number, are the otolaryngic allergists who face the same professional marginalization in allergy as food allergists once did.

food and environmental allergies, and the other consisting of tracking down and interviewing individuals prominent in the food allergy world. I had already begun building strong relationships with the ENT allergist and an acquaintance of his, a general allergist, at two teaching hospitals in my city, both of whom mostly saw environmental allergy patients. Rather than forego the robust access to clinical expertise that these physicians were enthusiastic about providing, I followed through on my early plans to shadow them and continue to learn more about clinical approaches to allergy. I also conducted qualitative, open-ended life history style interviews with a mix of food, ENT, and general allergists who I had already made contact with, mostly through my two initial allergist contacts. To connect with the food allergy community, I made more contacts with people at food allergy non-profits, food allergy bloggers, speakers at food allergy events, and food allergy-focused physicians. I conducted qualitative, open-ended life history style interviews with these individuals just as I was doing with allergists. I also researched and signed up for as many food allergy conferences and events as I could throughout the United States, in order to make new contacts for interviews and experience these events as a participant observer. The travel and fees required for participant observation at these events was supported by a number of research grants[5].

Let me backtrack for a moment to describe in more depth my research practices while shadowing the two allergists in their clinics. I shadowed the general allergist intermittently over the course of seven months for a total of about a dozen days and the ENT allergist once or twice a week for approximately five months. These activities went on concurrently in the first half of 2014. Even though the two physicians I shadowed happened to mostly treat environmental

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[5] This research was support by a Doctoral Dissertation Research Improvement Grant from the National Science Foundation (award number SES-1430489), Cornell University Provost Diversity Fellowship, a Cornell University Society for the Humanities Graduate Student Humanities Travel Research Grant, and a Cornell University Graduate Research Travel Grant.

allergies, the clinical techniques and scientific rationales were substantially similar to those of physicians whose practices leaned more toward food allergies. I might not witness cutting-edge food allergy research in their offices, but I would see top-notch general allergy and ENT allergy care. In addition, the ENT allergist led a yearly lecture series on allergy medicine for ENT residents at medical schools throughout the region. I attended his lectures, since it was a prime opportunity to get exposure to key concepts and resources in allergy medicine alongside some of the city's top medical residents, as well as to witness an often forgotten part of resident training in action.

I adopt the word "shadow" to describe my activities in the clinic from the American medical training jargon used by my informants. Witnessing medical procedures and simply spending time in medical facilities is a priority of American medical training; 100-hour resident work weeks are the most extreme expression of this, but it is common for future doctors to begin shadowing physicians as early as high school during school vacations. Medicine, like ethnography, values mere presence. A more familiar social science term for my method in the clinic would be "participant observation." However, given the highly – and appropriately – regulated environment of modern, Western-style clinical spaces, I wasn't able to do much "participation" in the two allergy clinics I spent time in. The inability to participate while observing in technoscientific communities is a key challenge posed by the study of elite, expert communities to traditional ethnographic methods (Forsythe 1990, Gusterson 1997). In the particular ethical and legal context of American medical training institutions, the most I could do was ferry blank forms from desk to desk during crunch time, or run down the hall to notify a nurse when a timer indicated a patient's wait for test results was over. This division of labor was implicit when I was lurking in the two offices and made explicit through the required online patient privacy training I completed before shadowing in the first clinic I entered.

In these two clinics, simply observing gave me the chance to become familiar with the spaces, the rhythms, the smells and sights and sounds of elite American medical facilities. I followed the physicians I shadowed from exam room to exam room when they had patients to see. I would be introduced as a PhD student from Cornell studying doctor-patient interactions surrounding the treatment of allergies. I would find an unobtrusive corner – seated in front of a window, leaning against the closed door – to watch and listen to the encounter. Between patient encounters I would quickly scribble an account of the procedures done, issues discussed, and interesting turns of phrase uttered in a two-dollar knockoff Moleskine notebook. During lulls, I was sent off to spend time with each physician's specialized allergy nurse while the physician answered emails or returned phone calls. It was in those moments that I could ask about unfamiliar terminology. Some days I would opt to spend extra time with the nurses to learn about the vials, liquids, skin prick apparatuses, and notetaking systems that make up the nitty gritty details of allergy diagnostics. During these moments, I openly took copious notes; extensive notetaking is a practice medical workers and ethnographers have in common, and a practice that did not disturb my participants. While I wandered around the halls, I was accepted by the residents as more or less one of them – another journeyman professional – and treated with similar respect and distance as a mid-level administrator by the physicians, nurses, and support staff.

Refocusing my research efforts on food allergies in the United States meant trying to find my way in a new community. Instead of following the ill-defined "community of allergy sufferers in the US," I was now researching a community with its own internal organization, philosophy, and structure. I had become familiar with a slice of the allergy physician community in my city, either through meeting members through my existing contacts or by reputation, but few of the faces in that circle were prominent in the food allergy world. The interviews I had done with leaders and members of area food allergy support groups were highly valuable in directing me through this pivot. Not only had I collected some highly relevant data on living with food allergies and caring for food allergic children, I also had made contact with two support group leaders who were active in the food allergy advocacy world and could tell me where to look next.

It was at this point that my project became truly multi-sited. In addition to continuing my relationships with physicians in my city, I identified a number of conferences and events throughout the US to attend. By showing up at these in-person events, I hoped to meet a wide variety of people living with food allergies as well as the physicians-researchers trying to explain the disease. Previously, my "site" was the network of teaching hospitals in my city, with a particular focus on two institutions – multi-sited in a literal sense but still geographically contained. By branching out to include food allergy patients and patient-oriented groups and events, I hoped to identify what ideas about food allergy research and treatment patients and physicians shared. Importantly, I hoped to learn more about how patients encountered, interpreted, and used official biomedical knowledge about the condition in their own lives – to understand how patients *live with* biomedical knowledge, including knowledge about risk, safety, and the "correct" way to care for someone with a chronic condition like food allergies. The intention was not exactly to compare differences in understanding between experts and the lay public, but rather to follow how core ideas morphed as they moved from the page of medical journals through the exam room out into the homes and lives of patients.

I identified 7 conferences and events to attend over the course of nearly two years: an educational night led by a local advocacy group just outside my city in March 2014, a national food allergy advocacy conference in June 2014 and May 2015 (the first year in the Midwest and second on the west coast), a conference in my city targeting food allergy-friendly restaurateurs and food service providers in October 2014, a major scientific conference on allergy held in the south in February 2015, and a conference of the burgeoning food allergy bloggers community in September 2014 and November 2015 (both years held in southwestern cities). These events allowed me to interact with participants as a true participant-observer: a lay expert in food allergy there to learn more about how to live with the disease and to network with others concerned about it. Still armed with my knockoff Moleskines, I took notes on the major concerns, lectures, and general goings-on at each event. As I travelled from city to city, I met people I had only heard of via the grapevine or encountered online and followed up with many of them in one-on-one phone interviews after the dust had settled from travel.

My project also took on a virtual dimension in May 2014. I began reading several food allergy blogs in early 2014, and I realized that the easiest way to get better acquainted with the food allergy advocacy community was to follow and join their public, online conversations, many of which were taking place at that time on the social networking platform Twitter. Here I discovered lively conversations that included mothers, advocates, specialty food businesses, and publicly engaged physician-scientists talking about food allergies. Conversations carried on in this 140-character format included decontextualized short text messages highlighting statistics about the number of people affected by food allergies, announcements about live events and educational webinars, links to news articles about food allergy research and deaths, tweets (the name for messages sent through Twitter) about conference goings-on shared and re-shared during events, and conversations about these materials carried out between acquaintances and friends on the public-facing side of the platform. In my research and in this dissertation, I treat the digital space of Twitter – and the public blogs, news websites, and forums to which Twitter users often linked – as extensions of "real life," another "site" in my multi-sited ethnography. Perhaps this is an artifact of my age – the fact that I am a "digital native." But in use, online spaces functioned as an extension of "meatspace" for the food allergy community. It played the role of telephone (but asynchronous and more convenient for coordinating conversation across time zones), mail service (but cheaper and faster), and bulletin board (but without the use requirement of physical proximity). While other researchers have troubled the status of virtual worlds vis a vis the material world (Hine 2005; Boellstorff 2006, 2010; Boellstorff et al. 2012; Golub 2010, 2010), this is not a primary theoretical concern for this dissertation. Using virtual communications platforms is, in general, treated in this document as another tool and space within which my participants act to raise awareness about food allergies. In doing so, I use *their* understandings of virtual space.

In the end, my two years of wandering around the allergy world produced multiple kinds of materials with which to write this dissertation: traditional field notes from time spent shadowing physicians and attending conference and events, interspersed with my written reflections; more than 60 recorded interviews totaling more than 37 hours of audio; at least a dozen more interviews recorded only in notes due to participant preference or convenience; computer folders containing dozens of scientific papers, online news articles, and blog posts as PDF files; a shelf of memoirs, popular science articles, cookbooks and how-to guides to living with food allergies written and/or read by my participants; and my own digital archive contained in my @allergyPhD Twitter profile where I posted and reposted interesting material I came across in my research for the public (and which is now being put to more general uses related to my scholarly persona) and my research diary blog, Allergy and the City. In my analysis, I dip into and out of these different archival materials and textual genres, carefully situating each in time, place, platform, and medium. Together, these materials form a multimedia, fragmented but faithful, record of my research.

### Science Studies and Ethnography: Three Perspectives from STS and Anthropology

The text that follows is an ethnography – a representative of a now-traditional "powerful scientific and literary genre" – produced through the analysis of qualitative, ethnographic field data (Clifford 1983, 123). In the tradition of anthropological ethnography, the work is based on extended immersion in a community with distinctive values and practices. The analysis is "centered on the experience of the participant-observing scholar" and makes use of ethnographic moments, that is, vignettes which provide time- and space-bounded synecdoche for the social dynamics at large in the world of food allergy (Clifford 1983, 128). These are some of the traditionally vital tools for reporting and interpreting evidence in ethnography that I draw on to make my arguments.

This ethnography is also a document of its time and of the milieu under study. Biomedicine is a global phenomenon that contributes to, and often dominates, how people worldwide interpret their bodily and mental ills. As a result, it is difficult to understand a biomedical phenomenon bracketed off from the global flows of knowledge, power, prestige, and capital (Lakoff 2004, 2005). Food allergy follows the pattern of other specialties and diseases in that the disease circulates as an object of concern at local, regional, national, and international levels. Approaches to studying and managing it are united by some common assumptions and understandings, gratis the universalizing tendencies of modern biomedicine (Warner 1997), but these concepts are often operationalized in different ways in local geographies and communities. Commonalities concerning perceptions of the “facts” of food allergy across scale and space are underwritten by the authority of medical and biological science, codified through the use of technologies like medical journals and professional conferences and disseminated via expert-approved patient advocacy groups with the help of a small number of publicly engaged clinician-scientists. Understanding the advocacy work done on behalf of people with the disease requires, first of all, understanding the notion of food allergies as a biomedical entity that informs their work, and second, following these individuals from place to place and setting to setting as they engage in their work.

How to conduct an ethnography that is sensitive to how networks of authority and representation interlock within and between different scales of social organization has become a central concern for ethnographers of global phenomena and expert communities. In the rest of this section, I will explore three conceptual themes that scholars have elaborated to address these issues: studying up, multi-sited ethnography, and symmetry. These perspectives on conducting ethnographic research on technologically sophisticated and socially authoritative cultures have shaped my research methods, and in turn my understanding of the food allergy “community” and its unifying concerns.

### Studying Up

Conducting an ethnography of scientific or technically skilled communities often places the ethnographer in a position of “studying up,” an idea with a long, and at times fraught, history in anthropological quarters (Nader 1974, Forsythe 1990, Gusterson 1997). Nader famously argues that “‘[s]tudying up’ as well as down would lead us to ask many ‘common sense’ questions in reverse” (6). In ethnographies of scientific fields, this can mean asking simple questions about why one tool, record-keeping system, or medical intervention is used in elite practices instead of another as much as understanding the complex bureaucratic structures or the scientific concepts with which their work is nominally concerned. The answers to mundane questions about how the work of elites is actually done can, on the one hand, inform and deepen investigations into traditional categories of ethnographic inquiry like kinship, economy. and ritual. By now, decades of studying up has illustrated that these "traditional" elements of social life persist even in bureaucratic or technoscientific settings where the elite culture under study denies their relevance. At the same time, ethnographically accessible practices and stories behind their work reveals that elite communities indeed have "culture" which shapes their scientific work, a revelation which can be as surprising for an ethnographer initially in awe of a community's prestige as it may be for the community itself. Internal power struggles, hierarchies, beliefs, rivalries with neighboring tribes, and so on all determine what a single community's work is designed to accomplish and what results are considered successful. Understanding these rich cultural worlds is of vital importance to the societies in which elite communities are embedded because in modern political regimes technical knowledge of the world often shapes attitudes about who or what is valuable or problematic, in turn shaping the allocation of concrete responses concerning funding, legislation, and legal action.

Studying up also changes the power dynamics between an ethnographer and her informants (Forsythe 1990). For one, it can be assumed that ethnographic analyses and critiques will be read by at least some of one's informants. This poses challenges to the ethnographer interested in critiquing the culture of an elite community. There can be harmful consequences for the ethnographer's own reputation if support from the community under study is necessary for the continuation of research or career. Moreover, in fields where a high level of skill or technical certification is needed for full participation, the ethnographer may become the last one in the pecking order, assigned to carry out the least desirable task in the office or lab. While this is not unique to conducting ethnography on elite communities, the low barrier to accessing some aspects of elite life due to shared language, class, or cultural references can seem at odds with the strict limits placed on participation in the production of knowledge, control of flows of capital, or bureaucratic decisionmaking that comprise the explicit goal of the organization. In most cases, this cognitive dissonance is fundamental to the practice of studying up.

Sometimes the inversions of studying up are framed playfully. Bruno Latour's early study with Steve Woolgar, *Laboratory Life* (Latour and Woolgar 1986), frames an ethnography of laboratory science as the study of an exotic tribe, analogous to the work of mid-century French anthropologists. Their framing deliberately playing with the reversal of the assumed differential in power and access to resources between the researcher and informants. The scientific workers under observation are not the audience, leaving Latour and Woolgar free to lace their ethnography with ironic commentary on their relationship with their informants. Others, like Joseph Dumit (2004, 2012), see their work among scientists as producing ethnographies that exemplify an ethical mandate to *speak to* scientists as well to other science studies scholars. Crafting ethnographies that include the experts under study as part of the readership can, perhaps, produce more reflexive scientists and better science. But for this to happen, ethnographers have to limit the degree to which their analyses might alienate their informants, potentially limiting the opportunity for critique.

The concept of "studying up" both did and did not apply to my ethnographic research. On the one hand, for the first several months I prioritized studying the allergy specialty in medicine, with a focus on physicians and physician training in a number of elite East coast teaching hospitals. There is no higher one can go in studying a biomedical specialty. My informants for this work were highly credentialed, some with MD/PhDs or other combinations of terminal degrees, and "above" me in the scientific pecking order. On the other hand, I entered the project with undergraduate and professional training in the life sciences, training that allowed me to become more of a scientific expert than even many of my patient advocacy informants. I have received a few invitations to speak and write publicly about food allergies as a social science expert on the topic. In another sphere of my life, I am "the science person" in a biotechnology start-up company because I follow the scholarly literature and am more tuned in to research on the food allergy than the company executives. Am I a scientific insider or outsider? Cultural background and social status also make it difficult for me to tell if I really have "studied up." My academic training puts me more on a level with the scientific experts I encountered in terms of cultural references and social status than with many of the advocates with comfortable middle-class incomes but lower levels of professional autonomy or accomplishment. Yet my own economic background would have afforded me less access to networks of power and prestige than anyone I spoke to, if not for the historical fluke of attending Cornell as an undergrad at a moment when the university was greatly expanding access to low-income students via financial aid.

So where is "up" for me, the ethnographer? Did I really study "up"? This is a difficulty constitutive of doing ethnographies of elite communities as a university-trained academic researcher. It has no easy technical or biographical answer. In the case of my research, the question is complicated further by the fact that both scientific elites *and* patient advocates – many of whom were middle-class women with skin in the game because of their traditional roles as mothers – participated. While physicians and PhDs were comfortable treating me as a high-level trainee (and their staff followed suit), parents and other advocates had a more difficult time classifying me. I was one of them (I had allergies), not one of them (I do not have children), and, for many, deserving of respect (since I was a scientist-in-training). With the advocacy community, where there was no clear script (few had encountered a PhD student, and fewer had encountered social scientists), my status in the relationship varied from moment to moment: sometimes I was respected as a scientist, sometimes I was seen as an equal who had "been there" with food allergies, and sometimes mothers told me I would never understand their opinions until I had kids. However, it is clear that the relationships I had with my informants were premised on a high degree of *sameness* rather than *difference*. We shared many middle-class American cultural references, reasonably successful track records at school, university, and employment, similar access to educational and professional credentials, and similar experiences living as part of nuclear families. Our political views concerning healthcare policy generally favored more enforcement of existing disability policies and more straightforward and universal health insurance coverage, a fact that probably arose from similar personal and professional interest in easing treatment access (or for physicians, for reimbursement) for food allergies. In the end, I would say I studied up, side-to-side, and maybe even down – a complicated juggling act for a green ethnographer.

### Multi-sited Ethnography

A second problem faced by ethnographers of science and technology is how to account for the connections across time and space that close analysis of scientific work and technical objects tends to reveal. In other words, what is the ethnographic "site" of interest for studying a technology or expert community? Since scientific knowledge is observed – and by now even assumed – to be dispersed across spatially extensive expert networks (Callon 1986, Law 1986, Latour 1987), an ethnographic approach limited to a particular locale would only provide the most fragmentary glimpse of the practice, context, and effects of modern technoscience. Multi-sited ethnography offers a way to do ethnographic research under conditions which once would have been antithetical to ethnography's founding epistemological assumptions that a culture can be identified in part by its presence in a bounded geographic location (Marcus 1995).

A strength of multi-sited ethnography for my research was that it allowed me to collect data on a variety of social groups and social interactions. It is appropriate for the study of a disease category like food allergy because such objects travel by necessity between different social worlds and physical locations with the people who have the disease, the researchers who study it, the policy makers who concern themselves with offering protection for sufferers, and so on. As I described earlier, the research for this dissertation took place in multiple sites, including several medical offices affiliated with or located within teaching hospitals, conferences at sites throughout the US, virtual spaces like Twitter and blogs, and my home office, where I sat during phone interviews. All of these "sites" were useful, yet they yielded different forms of data. Immersion in medical offices yielded observational data about medical practice and physician-patient interactions, for example. By contrast, attendance at patient and advocacy conferences revealed the key pharmaceutical players in allergy, how select physicians guide the scientific understanding of the patient community, and what values are important to patients and advocates.

Through engagement with multiple sites and communities, I was able to build a comprehensive understanding of the social potency of the disease called "food allergy." What it means to physicians is based in biological "facts" about human physiology, behavior, and immunity (some of which were introduced in the introduction), but what it means to parents of food allergic kids also concerns social inclusion, school accommodations, and the desire to protect vulnerable children. For professionals working in advocacy organizations and specialty food companies, it is their *raison d'etre*, while for pharmaceutical companies it is a diagnostic category that can be turned into a risk object that generates financial value. In fact, food allergy is all of these things, as well as various permutations of multiple of them. Studying a disease in this era of biomedicine means seeking to understand its many dimensions, including its biosocial, financial, epistemological, ontological, practical, and moral dimensions. This dissertation often focuses on the moral valence of food allergy within the advocacy community, but it does so through analyzing engagements of patients, caretakers, and advocates with other parties who are motivated by other interests.

One challenge of multi-sited ethnography is the diverse collection of materials which can be collected as "evidence" by the fieldworker. Studying a group at a distance or studying a group in which one can only be a partial participant (for example, calling in to an in-person meeting) means that field notes informed by experience cannot tell the whole story. In light of these difficulties, Hugh Gusterson (1997) has made the case for what he calls "polymorphous engagement":

> Polymorphous engagement means interacting with informants across a number of dispersed sites, not just in local communities, and sometimes in virtual form; and it means collecting data eclectically from a disparate array of sources in many different ways. Polymorphous engagement preserves the pragmatic amateurism that has characterized anthropological research, but displaces it away from a fetishistic obsession with participant observation. (Gusterson 1997, 116)

This multi-modal approach to data collection allows ethnography to adapt to the conditions found in different sites. It also opens up space for ethnographers conducting research in a technologically networked world to consider all social data, real or virtual, conducted via text, sound, video, or face-to-face interaction. Such a catholic approach has been integral to my own ethnographic data collection.

Polymorphous engagement with multi-sited data collection presents its own challenges. One question is how to combine various forms of data in a way that balances ethnographic particularity with the commonalities that link the multiple sites under study in a way which makes them attractive to the ethnographer in the first place. If anything, my work stresses common values and shared moral attitudes over particular dissentions and controversies within the community. This is in the service of telling a particular kind of story: a story that is primarily concerned with elucidating the uses of a disease category over a minute exploration of the struggles that contributed to its construction. Put another way, I am interested in how multiple enactments – or what Ammemarie Mol considers to be multiple ontologies – of a disease category are coordinated into an object that is recognizable to a wide variety of actors (Willems 1998, Mol 2002, Langwick 2011). This coordination is accomplished through the kinds of social activities I observed in my ethnographic fieldwork: patient education, advocacy and scientific conferences, and the circulation of patient testimonies via social media, cookbooks, blogs, and memoirs.

Charles Rosenberg (1992) argues for studying disease categories in a way that is sensitive to both the material properties of the disease and the social action it provokes:

> Disease is irrevocably a social actor, that is, a factor in a structured configuration of social interactions. But the boundaries within which it can play its social role are often shaped by its biological character … The biological character of particular ills defines both public health policies and therapeutic options. (Rosenberg 1992, xx)

Understanding disease categories as social actors requires paying attention to both its material (biological) and semiotic aspects, as well as the social consequences of its construction and deployment. Multi-sited ethnographic methods that enable polymorphous engagement with places, people, interactions, and things furnish one way to accomplish a thorough examination of these multiple dimensions of a disease category. This dissertation uses these tactics to tell a story about a disease. The story it tells is focused on the perspective of the US food allergy advocacy community but reaches out through the networks of scientific, administrative, and experiential expertise to understand how that community is situated in larger discourses about health, illness, biomedical knowledge, the financial interests at stake in disease advocacy, and the moral sensibilities that bind these various regimes together.

### Symmetry

Another unique challenge of conducting ethnographic research on a biomedical object like a disease is how to position oneself with regard to scientific "facts". STS scholars have a complicated relationship with scientific facts, having observed throughout the history of the field the ways in which they are "constructed" (Latour and Woolgar 1986) or "enacted" (Mol 2002) by scientific experts with the help of technological instruments. Sometimes these instruments are obfuscatory; at best, they can be assumed to give an always-partial view of the thing under examination. Within scientific communities, facts can be taken as given, due to faith in the mechanisms – technological, professional, and human – that produced them, at least until social crises undermine the credibility of their modes of production (Latour 1987, Wynne 1992). Attuned to the social dynamics that produce scientific facts, science studies scholars have traditionally privileged a "symmetrical" reading of orthodox science and external challenges to scientific facts (Barnes and Bloor 1986), rarely offering their own views on the facticity of scientific knowledge, and even less often revealing their own normative political stance toward their actors' activities. A symmetrical analysis often has the effect of an implicit critique of the stabilized (Pinch and Bijker 1984; Kline and Pinch 1996) technology or scientific theory. Whether or not this goal is attainable, or merely "result[s] in a re-balancing, if not a reversal, of values and positional strengths," remains debatable (Pels 1996, 284).

The principle of symmetry is being put to the test in new ways, particularly by environmental historians who invest similar credulity (rather than symmetrical skepticism) in documented scientific knowledge and social activity. Gregg Mitman (2007) and Nancy Langston (2010), for example, have heavily relied on scientific explanations of biological life alongside qualitative, historical data about social life as a tool for exploring the material connections between human industrial activity and the health of humans and other species. In this new twist on symmetry, life scientists are seen to offer detailed descriptions of the material properties of biological life that can serve as useful resources for materialist analyses. Medical anthropologists are undergoing a similar awakening. Ongoing conversations about "bioculturalism," championed by contributors to the interdisciplinary, online project Somatosphere, is an indication of this turn (Snodgrass 2015). Even feminist theory is now re-encountering "the biological" (Wilson 2015).

As an ethnographer of a community well-versed in the scientific theories about their shared object of concern, an anthropologist staunchly committed to acknowledging and accounting for the materiality of human bodies (Scheper-Hughes and Lock 1987), and an STS scholar interested in allowing space for symmetrical analysis, these antecedents are all in play in my research. By offering a method for excavating the could-have-beens, symmetrical analysis often shows that what *is* is not the same as what *ought to be* according to either the analyst or the actors under study. Yet when such an analysis is deployed upon a patient's experience of disease or a mother's desire to protect her children from harm, it morphs into a critique of ways of life, of ethical systems, of modes of moral reasoning. Just as there may be different ethical standards for studying different kinds of actors (Forsythe 1990), perhaps there are different degrees to which a symmetrical stance ought to be assumed depending on the actors involved. This dissertation equivocates on how best to resolve this tension by focusing on the work of patient activists over the work of immunologists, lawmakers, or drug company staff. How best to resolve this tension remains for future research and the book.

## From the World to the Page

Hugh Gusterson (1997) describes the challenge of contemporary ethnography as a matter of how to “write the global and the local onto one another” (199). The technologies and practices characteristic of expert scientific communities and the global circulation of people that defines elite technical training make it difficult to maintain clear distinctions between here and there, large and small, global and local in modern biomedicine. This dissertation has the global scale baked into its production: scientific knowledge from around the global informs the understandings of food allergies held by my informants and me, and I traveled throughout the country to gather evidence for this document. It also brings dispersed actors into proximity by treating the “virtual” world of Internet-based social media as part of the “real” social world – how it is lived by many of my informants. What follows is a thoroughly modern ethnography, with technologically-mediated manipulations of space and presence providing the matrix for understanding (bio)social connections, embodied disease experience, and the politics that emerge from their collision. Given the traditional primacy of experience in the production of ethnographic knowledge, shifts in scale and changes in what it means to “be there” with one’s informants has implications for what kind of ethnographic knowledge is produced.

Writing ethnography is, now more than ever, a work of assemblage, combining both archival and experiential evidence, and in the process redefining what “ethnography” can be. The hybrid, sometimes fragmentary character of some recent STS-influenced ethnographies seeks to tell a less partial truth about the world by assembling multiple forms of knowledge from multiple voices (Fortun 2012). Annemarie Mol’s (2002) parallel structure juxtaposes one text reporting her ethnographic observations of a Dutch hospital’s treatment of atherosclerosis with a separate, lengthy discussion of the theoretical development of STS and of her own attitudes toward her subjects. Kim Fortun (2001), meanwhile, includes documents and textual fragments from her participants to show the plurality of improvised tactics and positions adopted in the aftermath of the Union Carbide chemical spill in Bhopal, India. These narrative strategies draw attention to the always-incomplete nature of the stories that ethnographies tell about ourselves and others.

The narrative innovations of this approach appeal to me as a reader, yet in my own fieldwork I became concerned with how and why my informants said such similar things about the needs of patients with food allergies. Differences were minimized in favor of articulating a unified face for food allergy in both public discourse and more private, one-on-one conversations. For my informants, the various platforms and sites where I encountered them were all linked by a narrative about the common dangers of life with food allergies and the common goals (more research, more awareness, and more legislation) to seek to ease those challenges. What interested me as I got to know this community is how people from many professions and life circumstances could be brought into alignment on key issues like safety, prevention, and the basic biological “facts” of food allergy. To answer this question, this dissertation explores how multiple ways of knowing and talking about food allergy become integrated through the awareness campaigns and individual connections that hold the food allergy community together. I therefore treat the various types of sources I used as evidence as being integrated rather than fragmented, calling attention to the similar values, assumptions, and affects that are transmitted across multiple platforms, in multiple spaces, both synchronously and asynchronously. This dissertation tells a story about coherence and shared meaning across time and space, race and class – a story about a disease identity that unites a community around certain moral commitments and life history expectations.

# CHAPTER 3

# THE MORAL LIFE OF EPINEPHRINE

The first time it occurred to me to think of epinephrine auto-injectors as having a ‘moral life,’ I was sitting in a middle school auditorium in a well-to-do suburb of a major east coast city in the United States on a cold March evening in 2014. A well-known allergist from a major medical center in the region was finishing his lecture to a group of school nurses about the importance of using epinephrine auto-injectors to treat kids with food allergies who have life-threatening allergic reactions. In his view, there was an equivalence between anaphylaxis (a serious, multisystem allergic reaction) and epinephrine. Echoing current medical consensus (Sicherer and Sampson 2010), he considered epinephrine *the* treatment for anaphylaxis; when anaphylaxis is suspected, epinephrine should always be used. As the allergist repeated during his talk, “anaphylaxis *is* epinephrine.” One nurse sitting a few seats away from me raised her hand after the talk. She explained that she cared deeply about the kids at her school and that she would be very upset if a child died from an allergic reaction on her watch. The kids at her school were “her kids,” and the responsibility for keeping them safe and healthy weighed heavily on her. As she spoke, other nurses nodded and mumbled in sympathy. The growing number of children with food allergies was reflected among the students at this particular nurse’s school. Her responsibility for keeping kids safe was growing with the rise in childhood food allergies. Knowing how to administer epinephrine by using an epinephrine auto-injector would make this duty easier to accept.

Throughout the United States, managing food allergies is a growing part of a school nurse’s job.  According to a widely circulated report by the United States Centers for Disease Control and Prevention (CDC), the incidence of food allergies among children under 18 rose from 3.4% in surveys conducted from 1997-1999 to 5.1% in surveys conducted from 2009-2011 (Jackson et al. 2013). Peanut allergy comprises a significant portion of food allergy in children, accounting for approximately 25% of childhood food allergies, or 1.5% of all children in the US. The persistence of peanut dust in living environments and the resistance of peanut proteins to breakdown when heated are thought to contribute to the high rate of peanut allergies, while the ubiquity of the food in the American diet and its oiliness that makes it stick to surfaces and in food processing equipment makes it particularly difficult to avoid (Lack et al. 2003, Lack 2012, Du Toit et al. 2015). Peanut allergy poses particular challenges to schools and school nurses trying to balance the need of children with food allergies with the desires of other children because of the significance of peanut butter as a food of American childhood (Waggoner 2013). Banning that food from part or all of a school campus can create logistical challenges – how best to clean peanut butter off school lunchroom tables, playgrounds, toys, and desks? – as well as ill-will from parents of non-allergic kids. Nurses also coordinate access to emergency medications, including epinephrine. As I will discuss in more detail in this chapter and in chapter 6, how best to store, track, and distribute epinephrine auto-injectors is still a contentious issue. School nurses are typically on the front lines of balancing safety, convenience, and preferences in schools with food allergic children, most often without the kind of specialized training I witnessed.

This ethnographic moment is suggestive of the way that epinephrine auto-injectors – emergency medications that stop serious allergic reactions – shape both the capacity and moral duty of people with food allergies and their caretakers to provide care during acute allergic reactions. In this chapter, I use the term “moral life” to denote the meanings and uses that epinephrine auto-injectors take on as they circulate materially and discursively within the food allergy community in the United States. This ‘life’ can be followed in many directions; here, informed by roughly two years of ethnographic research, I follow how the device is commonly encountered in everyday life with food allergies and in the food allergy advocacy realm. I begin by examining features of the device itself before following it from the doctor-patient encounter in the clinic to the home of a family with a food allergic child to the online platforms people in the food allergy community use to share their personal food allergy narratives. Following epinephrine's paths reveals how using and talking about auto-injectors structure obligations to care, medicate, and protect people with severe food allergies.

Studying the moral life of epinephrine provides a narrative framework for understanding the moral terrain presented by the everyday management of food allergies. Key moments of learning to live with food allergies revolve around epinephrine, such as preparing for allergic reactions by learning to use the device, reorienting family and social life around food allergies, and going online to find support from others managing the condition. By focusing on such unexceptional activities, my approach responds to Michael Lambek's (2010) call to study "ordinary ethics": "an ethics that is relatively tacit, grounded in agreement rather than rule, in practice rather than knowledge or belief, and happening without calling undue attention to itself" (p. 2). Cheryl Mattingly's recent work on "moral laboratories" – those moments in which different meanings of a 'good life' must be negotiated and brought into at least temporary alignment to enable action – offers one test of Lambek's program (Mattingly 2014b). Her analysis of such experimental moments shows how mundane encounters between individuals in contexts of medical crisis and material need can shape the meaning and practices of care, duty, and hope.

I seek to extend this line of inquiry, though, I take Lambek's proposition in a different direction than Mattingly does. Mattingly's lower-income, African-American informants are motivated by striving for a better life for their children – the ‘good life’ – in order to overcome the structural oppression and material deprivation in their current life circumstances. My informants, by contrast, are generally middle- to upper-middle class, mostly white and living in nuclear families, content to pass on their social status to the next generation rather than to improve it. Given my very different ethnographic context, I find that the moral questions concerning epinephrine auto-injectors that matter for my informants are less virtue-oriented and more immediate: they are questions about the duty to protect life in life-or-death situations. As this discussion the moral life of epinephrine will show, these questions are negotiated in a variety of mundane contexts in food allergic lives.

## Narrating the Moral Life of Medical Objects

I take Arjun Appadurai’s introduction to the 1986 edited volume *The Social Life of Things* as a way to structure the narrative about the moral life of epinephrine. It serves as jumping off point for thinking about how technological objects are animated by everyday moral reasoning. Appadurai argues for a shift in thinking about commodities from considering what economic value commodities have *qua* commodities to understanding how commodities take on economic value through the historical-material fact of being exchanged by people in a society. The ‘formal truth’ that exchange creates value is not enough, however; the methodological challenge for anthropologists, Appadurai writes, is to “follow the things themselves, for their meanings are inscribed in their forms, their uses, their trajectories…[in order to] interpret the human transactions and calculations that enliven things” (Appadurai 1986, 5). In proposing an analysis of the “social life” of things, Appadurai challenges the idea that the “value” of commodities is merely economic. Rather, his method reveals that economic and social value are in constant interplay – that “economic objects circulate in different *regimes of value* in space and time” (4).

Economic objects are also object of social value, of cultural interest, and of desire; they are subject to reciprocity typically taken to be characteristic of gift exchange; they are both material and semiotic. In short, Appadurai argues that bracketing "the economic" from other aspects of social life obscures the full sense of value and ignores how the economic is thoroughly social.

In this analysis of epinephrine auto-injectors, I modify Appadurai's approach to concentrate on how epinephrine auto-injectors accrue moral value. Their role as an indicator of moral responsibility and commitment emerges from the particular ways in which people in the food allergy community talk about them, use them, and educate others about them. Their moral value – where "the moral" is itself understood, as explained in the previous pages, to be a product and producer of sociality – does not stand separate from their economic value, nor from their physiological function as defined by biomedical science. Referring to the social trajectory of epinephrine auto-injectors as a 'moral life' communicates the ongoing, malleable, and unpredictable nature of their moral significance to those who rely upon them.

The special problem posed by following *medical* objects like epinephrine auto-injectors is that their social value is linked to their practical capacity to shape the life course via interventions on the body. It is by now a truism among anthropologists that the body is intimately linked to subjective being, social life, and political belonging (Mauss 1973, Scheper-Hughes and Lock 1987, Csordas 1990, Geurts 2002). In diagnosing and curing what ails us physically, medical interventions have the potential to change how an individual experiences the world, understands herself, and relates to others; they shape kinship, non-kin social affiliations, identity groups, and political orientations (Dumit 1997, 2003, Healy 2004, Biehl and Moran-Thomas 2009). If bodily experience is, as Csordas (1990) famously argued, "the existential ground of culture," providing the baseline experience of the world which forms the foundation for cultural norms and practices and the means by which individuals in a society relate to one another, technologies that enable, prolong, or end human lives are morally potent objects (5). They have the capacity to make and destroy subjects and social worlds.

What is the meaning of "morality" that informs my analytic concept of the "moral life" of this medical object? In their introduction to a special issue of *Ethos* on moral experience, Zigon and Throop (2014) acknowledge that even among anthropologists who study it directly, morality lacks a precise theoretical definition. They argue that the emerging sense of this concept in anthropology shifts the working definition of morality from the register of the normative, as intended by moral philosophers and bioethicists, to an "attuned concern for the relationality that constitutes our very existence" (Zigon and Throop 2014: 3). In other words, what happens when we think about morality as an integrated element of sociality, rather than an imposed constraint upon it? In what ways do social arrangements give rise to expectations about what is good and right if we suspend the lay expectation that social life is governed by unshakeable moral codes? The study of moral experience, according to these authors, is the study of "our experiences of the world and how we might struggle to transform these experiences, to rethink them, to interpret them, to reinhabit them, and to reposition ourselves variously as sufferers or actors on the differing scenes that in part constitutes our social existence" (p. 8). Studying morality as a product of sociality offers possibilities for rethinking (potentially harmful) patterns of social interaction by undermining the idea that absolute moral principles drive our prejudices and privileges.

Following scholars like Zigon, Throop, Lambek, and Mattingly, I propose that situated (Haraway 1988) forms of moral reasoning emerge from the interplay between objects and users, between action and reflection, and between the fulfillment of expectations and simply making do. I understand morality to be an aspect of human experience that both structures and results from activities that enact relations of care, responsibility, and obligation. “The moral” encompasses those cultural logics – logics that can morph into new configurations depending on the context or the problem at hand. What is considered to be the “right” way to care for someone with food allergies, both technically and morally, emerges from properties of the tools available to manage the disease – epinephrine auto-injectors – and the pre-existing social arrangements that organize encounters between family and community members, the medical profession, and food allergy activists who write for the public. Discussion among food allergy bloggers, informed by medical advice, has helped to solidify and publicize a procedural doctrine to deal with what has come to be accepted as an indisputable series of connected “facts”: food allergy causes anaphylaxis, anaphylaxis causes death, and epinephrine reverses anaphylaxis. The food allergy world is a particularly interesting place to explore this notion of “the moral” at this moment because the specific caretaking practices associated with this condition challenge what we think of as “taking care of” someone with illness in the first place: they are focused on anticipation and heroic intervention, rather than curing, medicating, and nurturing. In the food allergy world, using epinephrine auto-injectors shapes what is considered responsible and morally correct, illustrating how the moral ties between people needing care and those who care for them are enacted.

### Epinephrine Auto-injectors: Objects, Companions, Commodities

Epinephrine (also known by its Latinate name, adrenaline) is a hormone and neurotransmitter produced by the human body in the adrenal glands. It acts on the circulatory system by stimulating the heart muscle and constricting blood vessels, called vasoconstriction, and on the nervous system by producing the ‘fight or flight’ response. When administered during the severe, multi-system allergic reaction called ‘anaphylaxis,’ epinephrine stops the blood vessel leakage that causes the symptoms of anaphylaxis, including hives, redness, and swelling of the airways.

Anaphylaxis symptoms typically begin minutes to hours after an allergic person is exposed to an allergen, and they can recur in a second wave four to six hours after the reaction initially begins. Common symptoms include respiratory symptoms (such as wheezing or airway obstruction), skin symptoms (hives, swelling, redness), gastrointestinal symptoms (vomiting, diarrhea), cardiovascular symptoms (lowered blood pressure), and neurological symptoms (“feeling of doom”). Anaphylaxis is most readily recognized when more than one body system is involved, though treatment with epinephrine is now recommended as soon as symptoms begin. A dose of epinephrine halts the reaction within second to minutes, constricting blood vessels to stop the blood vessel leakage that produces symptoms and allowing the body to reabsorb stray fluid. Patients are taught that, without treatment and follow-up observation by medical professionals, anaphylaxis can easily lead to death (Simons et al. 2014).

Outside the hospital setting, epinephrine is most often delivered to a patient using an epinephrine auto-injector. Epinephrine is considered a ‘rescue medication’ with a short duration but dramatic effects, to be used to halt symptoms after they begin but not to prevent them. Auto-injectors are designed to be used by the patient, though they are increasingly pitched as easy for untrained onlookers to use as well. They consist of a needle, a dose of medication, and a protective plastic case that covers the needle before and after use. Food allergy patients are counseled by physicians to keep two auto-injector devices on their person at all times. The second injector can be used if the first fails, if there is a delay in getting the person to the hospital, or if their reaction is so severe that they continue to react after the first injection. Medical guidelines emphasize that prompt use of epinephrine is the primary method for reducing the risk of serious injury (such as brain damage) or death resulting from anaphylaxis (Simons et al. 2014). After using epinephrine, patients are advised to go to the hospital for monitoring in case the reaction comes back or the second, later wave occurs (but not because epinephrine itself is considered dangerous). It is considered better to use epinephrine, even if it is unnecessary, than to fail to use it when it is necessary. Side effects of the medication can include a feeling of weakness, sweating, raised blood pressure, and a racing heart – signs of the “fight or flight” response that epinephrine is designed to provoke in ordinary circumstances, and symptoms that are secondary to its life-saving circulatory system effects. Serious adverse events due to epinephrine itself are essentially undocumented with currently available delivery devices, which contain carefully metered doses of medication. In medical parlance, ‘there is no absolute contraindication’ to the use of this medication (Simons et al 2011).

Two epinephrine auto-injectors dominated both the market and the popular imagination in 2015, Mylan’s EpiPen (re-launched under Mylan’s brand in 2007) and Sanofi’s Auvi-Q (launched just before I began my research, in January 2013). A generic version is also available, though I have never heard of anyone choosing to use it in two years of ethnographic research, and a third branded version, Japanese pharma giant Shionogi’s Twinject, was removed from the market in 2012. Both the Auvi-Q and EpiPen work in roughly the same way: the device is removed from a protective case, a piece of plastic is removed from one end that activates the device and makes it possible to expose the needle, and the patient quickly swings the needle end into the large muscles on the outer side of their upper thigh. The device strikes the thigh and clicks, injecting the medication while it is held in place for five to ten seconds. The needle retracts to protect the patient from unnecessary sticks when the device is removed from the surface of the body. Both devices come in two strengths, a 0.3 mg dose intended for children and adults weighing over 66 lbs., and the 0.15 mg version intended for children 15-66 lbs. Patients and caretakers are counseled to carefully monitor and protect their auto-injectors: epinephrine is a finicky molecule that is only stable within a narrow temperature range and the devices have only a one-year shelf life from the date of manufacture.

*Figure 1. Epinephrine auto-injector training devices, identical to size and shape of medication-delivering prescription devices, with a pen for scale.*

Sanofi’s Auvi-Q has a special feature which deepens its moral entanglement with the user. It speaks to users in a pre-recorded, slightly mechanical woman’s voice, guiding the user through the process of using the device. This feature is not an innocent innovation. The choice of a female voice suggests a mother, auntie, or nurse who is patiently and willingly inhabiting the female-gendered role of caretaker. It speaks in measured, clearly articulated Standard American English, conveying a sense of calm and competency with careful, unhurried diction. The voice is there to help, to guide, but not to command. The voice begins automatically when the device is removed from its case and pauses when it is time for the user to take each action in the sequence. Through its use of a human voice, it conveys the message that the user is not alone and will be taken care of in the event of an anaphylactic emergency. The user is invited to trust the device with their life by the device itself.

The voice feature inspires mixed feelings among my interlocutors. For some, it inspires a feeling of distinction. For example, one parent explained to me that her seven-year-old son is *proud* to carry his Auvi-Q with him. He keeps it in an oversized pocket of his cargo pants. His attachment to this object centers on its technological novelty: for him, it's not just medicine, it's his very own high-tech gadget that sets him apart from his peers. Since he likes the device, he is never without it, making him a responsible food allergy patient. One allergist, who has a peanut allergy himself, explained that the product was a much more practical shape to carry in his pocket and he had no opinion on the voice. Perhaps the physical design will encourage more people to keep it close, he mused when we discussed it. His allergy nurse colleague expressed discomfort and annoyance with the automated voice, preferring to teach patients to use a different, voiceless device. Many food allergy bloggers (most of whom are mothers of food allergic kids) appreciate a product that guides users through the injection process, especially for small children who may not be able to use the device on their own and may need an untrained adult to help them. For them, it is a way to make it easier for bystanders and caretakers to use the device for someone having a serious allergic reaction. The device's ability to voice instructions widens the circle of people who can be made morally responsible for those with serious food allergies.

In addition to being familiar fixtures of everyday life with food allergies, as I will discuss in depth in the sections that follow, epinephrine auto-injectors are big business for the pharmaceutical companies that make them. Like many players in the pharmaceutical industry at this moment, the profits they generate are growing not only due to wider use, but also due to rising retail prices. I began to hear grumbling about the rising prices of epinephrine auto-injectors in early 2015 on a number of food allergy blogs, in one-on-one conversations, and on Twitter. Later in 2015, a series of news reports on the rising price of these devices and a massive Auvi-Q recall put specific numbers on the trend of rising prices, while driving home the fact that these devices, portrayed as life-saving by physicians and activists, are also potentially fallible commodity objects. This coverage highlighted the fact that epinephrine auto-injectors have different kinds of value in different contexts, a fact which was troubling to many in the food allergy community.

An article by news outlet Bloomberg Business, released on September 23, 2015, underscored the commodity character of auto-injectors for the companies who manufacture them (Koons and Langreth 2015). This report confirmed what I had been hearing from advocates for months: the price of EpiPens has increased significantly, from $57 per device in 2007 when Mylan acquired the device to a typical price of $415 for a 2-pack (the way physicians now recommended patients purchase them) in 2015. The rise in prices, according to the Bloomberg report, contributed to a jump in revenue generated by the product, from $200 million in 2007 to over $1 billion with a 55% profit margin in 2015. It now makes up 40% of Mylan’s profits. Its “brand equity” – the feelings and product loyalty it inspires in customers – makes it impervious to competition from a generic manufacturer, according to CEO Heather Bresch. In the first half of 2015, their brand equity (along with, one might assume, the ubiquity of their sales force and marketing presence) supported an 85% claim on the market. For the company, the device is a hot commodity, one whose profitability is ensured by its image as a trustworthy, life-saving device, and revised medical recommendations that have doubled demand independent of any other factors.

Of course, pricing for these devices, as for all prescription pharmaceuticals and medical devices, is more complicated than simply paying the amount printed on a price tag. Mylan and Sanofi both made frequent use of co-pay discount cards for epinephrine auto-injectors. This marketing-tool-cum-social-support-program is used extensively for branded pharmaceuticals in the US today. Co-pay discount cards reduce the amount paid by patients with insurance coverage by a specified amount, or even down to zero (discount cards for auto-injectors often reduce the price by $100 or more, all told). This helps customers with good insurance coverage by leaving them with reasonable or no copays for prescriptions, but does little for those with high deductibles or poor prescription coverage, and nothing for the uninsured or for patients who happen to miss the news about copay promotions. While these programs were originally rolled out as temporary promotions by both companies on the heels of the Auvi-Q's release in early 2013, the expiration dates on these programs have been extended again and again, with new cards being distributed at conferences, in doctors' offices, and even directly to patients via online coupons. At this point, high asking prices for the devices seem to be in perpetual coexistence with generous subsidies from the companies themselves. Through the circulation of these copay reduction "gifts" (Oldani 2004), Mylan and Sanofi can appear to care for the economic situation of their customers, yet still reap significant profits from these devices quarter after quarter.

Another blow for epinephrine auto-injectors' reputation came on October 28, 2015 when Sanofi announced an enormous recall of Auvi-Q devices and the cessation of their production line. Devices with expiration dates spanning 14 months into the future were recalled – every Auvi-Q device on the market at that time (Sanofi 2015). The company cited production problems that seemed to have resulted in some devices receiving inadequate doses of the medication, potentially putting patients at risk of using ineffective devices. I was glancing at social media as I transitioned from phone calls to writing at 5:20 pm that Wednesday afternoon, roughly the moment of the initial announcement, which was pushed out, according to social media chatter, via Twitter before appearing in company news subscribers' email inboxes. My feed was exploding with the recall news. Soon, my Facebook feed lit up with the news as well. By 7 am the next morning, I had 28 notifications about the recall on Facebook, and my otherwise text-heavy Twitter feed was punctuated by the repeated thumbnail image of the Auvi-Q injectors.

A blog post on the food allergy advocacy website, Oh Mah Deehness!, run by attorney and food allergy activist Homa Woodrum, was representative of the reactions. Within a couple hours of the news, I clicked a link that she had tweeted and arrived at a blog post titled, "All Auvi-Q Epinephrine Autoinjectors Recalled." Her post suggested skepticism about the motivations behind the recall. She wrote, "You could view the recall as being in an abundance of caution and therefore showing how sensitive Sanofi is being to consumers or you can wonder about the timing and the lack of actual clear instructions for how to handle the issue." She reports that the recall came less than a week after she received an email from the company encouraging her to purchase more of their devices before the end of a promotional pricing program, piquing her suspicion about the motives of the drug company.

Deciding whether to trust in the company's remediation of the manufacturing defects that led to the recall was both an economic and moral decision for this writer:

> The costs of replacing medication, between new doctor's appointments for prescriptions, potentially missing work or school to sort matters out, and more are factors that Sanofi can't control.  I have preferred the Auvi-Q in form and function since it was released but

> will be sending my daughter to school tomorrow with a set of EpiPens. The sheer expense of a mid-year replacement (i.e., replacing the EpiPen with an Auvi-Q if new batches ship) make reverting back to the Auvi-Q another year away for us. (Woodrum 2015b)

The high price of replacing auto-injectors in the wake of this recall – especially given the ongoing rise in prices – makes a seemingly straightforward decision about providing an important medication to her daughter into a decision about the economic value of medical care and the (potential) monetary value of a human life. For Woodrum, the possibility of doubting medical guidance that two auto-injectors are necessary to have on hand at all times did not arise, but for some bloggers and advocates it did. Her comments underscore that epinephrine auto-injectors are troublesome to imagine as a financial commodity separate from their moral value as a life-preserving tool for people living with food allergies. There is felt to be no option to go without this device for people living with food allergies. When Sanofi's production line failed, patients and caretakers were confronted with the bare economic value of auto-injectors, sparking panic and anger.

Epinephrine auto-injectors are devices designed to safely and conveniently deliver an emergency dose of medication. They function as companions and caretakers to people who carry and may need to use them, and as commodities being sold by a drug company to people who, so far, have paid any price to purchase them (often benefiting from price supports offered through insurance and copay reduction cards). It is difficult for users to square their moral significance as life-saving objects with evidence of their economic value and the practical reality that they are potentially fallible. As the next sections will show, it takes work on many fronts to sustain the "life-saving" image of epinephrine auto-injectors given the economic cost of health care in the contemporary United States. Just as the economic value of auto-injectors must be constructed and supported via bureaucratic means, their moral value is (re)produced through patient encounters with medical professionals and the awareness campaigns of food allergy activists.

### Using Epinephrine in the Clinic

An individual’s first encounter with an epinephrine auto-injector typically occurs in their allergist’s office. Once the allergy is confirmed by their medical history or by diagnostic tests, the allergist prescribes an epinephrine auto-injector. The allergist or specialized allergy nurse then demonstrates how to use the device with an auto-injector “trainer”. Trainers do not contain medication but have the same mechanism, shape, and size as real auto-injectors. In the rehearsal, the patient vigorously swings the device onto their outer upper thigh and holds it in place for 5 to 10 seconds (depending on the device) to simulate the time it takes for the medication to be fully injected by the needle. Before and after, the physician counsels the patient on when to use the auto-injector, the importance of carrying it on their person at all times, the recommendation to go to the hospital and wait under observation for several hours following the use of epinephrine, and on the need to avoid any foods they are allergic to. Then the patient leaves, prescription in hand or sent electronically to their pharmacy of choice.

In interviews and casual conversations, patients and parents of food allergic children report to me that they left the doctor’s office feeling helpless following the initial food allergy diagnosis and auto-injector counseling. The procedure in the doctor’s office is, typically, narrowly focused on teaching patients two things: the danger of food allergies and, therefore, the importance of pharmaceutical preparedness. Being counseled in the use of an epinephrine auto-injector only teaches patients how to mitigate disaster when it arrives. Particularly conscientious allergists will suggest that the patient consult local support groups or websites, but the allergists themselves still offer little practical advice. For physicians, this is a necessary evil because there is no widely available therapy for treating or preventing food allergies.

The clinical encounter participates in the construction of food allergy (and a patient's particular allergenic foods) as a "risk object" (Hilgartner 1992), instilling an affective disposition priming the patient and/or caretaker to be prepared to act (Masco 2008, Adams, Murphy and Clarke 2009) and proposing a technological solution for managing the moment of crisis (Anderson 2010). The preparedness logic of the clinical encounter in food allergy mimics calls for preparedness in other areas of biomedicine (Jain 2007, Dumit 2012). This approach does not, however, give people who manage food allergies the practical tools they need to avoid the foods they are allergic to in the first place: how to read food labels, what to ask food manufacturers in order to learn whether allergens came in contact with their preferred foods, and how to assertively refuse allergenic foods offered by friends and family members. The paucity of information most patients receive about *how to live* with food allergies feels like an ethical lapse to many on the receiving end of biomedical advice.

By following the diagnostic and training procedures outlined above, allergists provide the best standard of care possible within the framework of evidence-based medicine, increasingly the norm in the clinical practice of allergy as in other areas of medicine (Kaufman 2015). In this paradigm of medical care, the evidence cited in the medical literature constitutes an (informal) law governing which treatments can and cannot be recommended. With food allergies, the evidence suggests that timely administration of epinephrine results in fewer deaths from anaphylactic reactions (Simons et al. 2013). In the US, deaths hover at around 100 per year, but hospitalizations are much more frequent, estimated at 2,200 per year for hospitalizations due primarily to food-induced anaphylaxis (Rudders et al. 2014). There are no studies in the mainstream allergy literature studying the techniques patients use to avoid allergens in the first place. Thus, for a physician to go out on a limb to make lifestyle recommendations based solely on patient reports – even if they are the physician’s own patients, and even if she has heard similar stories (or “anecdotes” as physicians sometimes call patient reports that exceed the bounds of medical histories) over and over again, and even if they are approaches recommended by patient support and advocacy groups – would be an ethical lapse according to the evidence-based mood of the contemporary allergy clinic. It would be a moral misstep to give medical advice concerning dietary management without statistically analyzed studies. At best, allergists will refer patients to counselors, nutritionists, or patient organizations specializing in managing food allergies, leaving the qualitative science of lifestyle management and interpersonal skills to these lower-paid, women-dominated professions.

Also ignored in the clinical encounter is any acknowledgement of the burden that dietary management and auto-injector use places upon patients. One survey of families with food allergic children estimated that the condition costs the average food allergy family between $3500 and $5000 per year. An estimated 31% of that amount comes from direct costs (like specialty foods, fees for private schools, medical care, and highly skilled child care) and the remainder coming from the opportunity cost of taking more flexible jobs or foregoing employment opportunities (Gupta et al. 2013). Fifteen percent or more of the total cost of food allergy is devoted just to purchasing specialized, “safe” foods, while roughly another 15% comes from trips to the ER and overnight hospital stays. A trip to the ER following auto-injector use, as recommended by medical authorities, is thus no small thing for many food allergy families. Epidemiological research looking at the mental health impacts of managing food allergies by patients and caretakers (especially mothers) demonstrate the social costs of the diagnosis as well

(Springston et al. 2010). Just as the value of epinephrine auto-injectors is more than biological or economic, a food allergy diagnosis impacts more than health: it also impacts feelings of social integration and the finances of an individual or family. The biomedical exhortation to preserve life based on evidence discounts these other, very real, very moral dimensions of life with food allergies.

Epinephrine auto-injectors are important devices for people with food allergies because of their material properties. These properties are the exclusive concern of the physicians who prescribe them in patient encounters. As knowledge about how to use auto-injectors is conveyed by physicians and nurses to their patients, their normative moral duty to treat using the best biomedical evidence available is fulfilled. Following this entrée to life with food allergies, however, patients find their social, financial, and moral needs at odds with the services most allergists are willing and ethically authorized to provide. Rather than allay anxieties, the new ambiguities that auto-injectors introduce help to make them a focal point for fears of illness and death. It is, as food allergy patients have been taught by their physicians, the one tool that can decide their fate.

## Epinephrine and the Moral Career of an Allergy Mom

The moral life of epinephrine is inextricable from the social lives of people living with food allergies – how they participate in social events, who they trust and rely upon, and how they carve out moments of safety within the swirl of existential threats posed by food allergies. At the scale of lived experience, epinephrine auto-injectors can act as lifesavers for individuals who carry and sometimes use them, but they also serve as a continual reminder of the social limitations imposed upon them by a food allergy diagnosis. In this section, I explore one woman’s trajectory to become an ‘allergy mom’: how she learned to live with food allergies, the role epinephrine played, and the moral challenges such a life presents.

Erving Goffman’s (1961) notion of the “moral career” is helpful for parsing the life histories of individuals living with food allergies. Using this framework foregrounds the social interactions that make up the moral negotiations that help to map the trajectory of a life with a chronic condition. In *Asylums*, Goffman describes what he calls the “moral career of the mental patient” who eventually becomes committed to an asylum as both a moral and social project (148-150). It is moral because diagnosis as a mental patient causes the person and those around him to reinterpret, and potentially rewrite, the story of his life and achievements, triggering a new understanding of himself, the moral qualities of those with whom he interacts, and the character of his relational bonds to others. It is social because induction into life as a mental patient requires breaking old social bonds organically formed through the life course and forming new, compulsory bonds with other inmates, with caretakers on the outside, and with orderlies, nurses, and doctors on the inside. The breaking and remaking of social bonds trigger the patient’s moral reevaluation of himself and those around him. Making an appropriate display of his reconfigured moral self is then the key to release from the institution. This trajectory can be derailed or facilitated by “contingencies” such as socioeconomic status, “visibility of the offense,” the proximity and kind of treatment available, and the actions taken on the patient’s behalf while he is institutionalized to ease the transition back into normal society (pp. 134-5). The patient learns to see himself differently and to adapt to a new social situation, with new alliances, enmities, standards of conduct, and moral codes that model what will be expected of him on the outside.

Similarly, in the context of social life and medical care in the United States today, a food allergy diagnosis forces an individual to reevaluate expectations for her own experience of the life course, strains existing social relationships, and enables the formation of new ones as a consequence of managing the disease. In the moral career of a food allergy mom, these interactions are delimited by the rigid biological limitations of what can and cannot be eaten, rather than by the walls and institutional organization of life in an asylum. In life history interviews with mothers of food allergic kids, I am often told about how a food allergy diagnosis leads to the breaking and (re)formation of many important relationships in their lives, including with members of the nuclear family and extended kin, colleagues, caretakers like babysitters and teachers, and other food allergic adults or parents of allergic kids. It complicates decisions about who to trust with caring for their children, puts interactions with school officials on contentious ground as they seek to limit the entry of allergenic foods into classrooms, and limits the civic and professional projects to which they can commit themselves.

The story told to me by one of my first contacts in the food allergy world exemplifies the moral career of a food allergy mom. This woman, who I will call Sarah, has two children with food allergies, both of whom were diagnosed as babies. She began suspecting there was something wrong with her first son when he began breaking out in “dynamic” rashes and eczema and having bloody, mucusy stools. His symptoms began when he was only four weeks old, while she was nursing him and eating her ordinary diet. Her second son exhibited similar symptoms several weeks after birth as well. Her pediatrician and allergist offered her epinephrine prescriptions and counseled her to avoid feeding her sons allergenic foods but provided little advice on how to live day to day with kids with food allergies.

As her children got old enough for neighborhood play groups, she recalls the stress these situations caused for her. Off-limit foods were everywhere, and other moms did not seem to care about helping her clean allergens like peanut butter off of play surfaces. Upset by what she called their "lack of awareness [and] lack of compassion," she decided to start a support group in her town for parents of food allergic kids. The support group allowed her to connect and commiserate with other moms in her community facing similar issues. As a leader of the group, she also made contact with national food allergy support and advocacy organizations, acting as a "human antenna" that linked the local group to national priorities and issues. She and the other mothers in the group found comfort in connecting with like-minded "food allergy moms". It was useful for everyone in the group to share ideas about how to deal with schoolteachers and officials and find allergy-friendly foods.

However, it did not turn out to be a panacea for the everyday stresses of living with food allergies. Her younger son, who was 7 years old at the time of our conversation, had recently begun experiencing anxiety arising from his food allergies. While Sarah explained that increased anxiety is developmentally appropriate for a child of his age, his anxiety is entirely focused on foods and eating, something she attributes to the constant vigilance required to manage his food allergies. It is especially distressing because his anxiety symptoms – a tight, sore throat – are identical to his earliest symptoms of an allergic reaction. The symptom overlap makes it difficult to know when a reaction is occurring, and thus when epinephrine ought to be used. Mealtime is complicated, too, since her two sons' allergies don't overlap. There is no hugging or kissing around mealtime until everyone has been washed up; dirty hands can (and have been) used as a weapon between siblings, who can develop rashes just from touching allergen residue. With one child allergic to dairy and the other allergic to soy, mixing up the dairy milk and the soy milk could result in serious illness.

Managing two kids with food allergies has also changed Sarah’s professional aspirations and self-image. She has had to put her career on hold in order to shuttle the kids to frequent doctors’ appointments, cook all meals at home, and advocate for her sons at school. She feels that she is constantly trying to “walk a line between seeming crazy and keeping these kids alive.”

Toward the end of our conversation, Sarah shared a pair of stories with me. First, she recounted the story of a sixth grader who ate a cookie with nuts in it while sitting shiva in a town with which she was familiar. Ensuing asthma symptoms were treated, but epinephrine wasn’t used because she didn’t tell her parents about eating the cookie. The girl died. Then Sarah told me the story of a 14-year-old boy who died in October 2013 after being in a coma for two weeks following a severe reaction to peanuts. This second story was familiar to me, since it had been circulating on the food allergy blogs in the previous weeks. The boy, Giovanni Cipriani, had eaten a snack mix containing unlabeled peanuts, a food to which he had a severe allergy. According to an essay Giovanni’s mother wrote for Food Allergy and Anaphylaxis Connection Team (FAACT), a food allergy advocacy and awareness organization, she did not inject him with epinephrine and call 911. Instead, she gave him antihistamines and drove him to a nearby emergency room by herself. By the time they arrived, he had stopped breathing. He fell into a coma and never recovered before passing away three weeks later (Cornago 2014).

Occurring as they did during of a conversation about her own life and children, I understood these stories as a way for Sarah to illustrate how dangerous it is for children to live “normal” lives with food allergies. Despite her efforts to manage mealtime and hygiene in the home and to build relationships with other mothers and community members who could help keep her kids safe, her kids would always be at risk of a deadly, unforeseen reaction. I also knew that these stories were being repeated on food allergy social media as a way to encourage the prompt use of epinephrine auto-injectors for allergic reactions to food. Epinephrine was front and center in these morality tales and illustrated the worst case scenario of what could happen with inadequate preparedness. Telling them was a way for her to teach me, a novice in the world of food allergies at the time, about the paramount importance of knowing how to carry and use epinephrine auto-injectors when raising or caring for food allergic children. They protect against the rebelliousness of teenagers, the recalcitrance of other moms, and the carelessness of food manufacturers – normal features of a food allergy mother's life.

This is the point at which the moral career of an allergy mom and the moral life of epinephrine intersect. Moms are most often the primary caretakers of food allergic kids, responsible both for following protocols for using epinephrine to fulfill their moral duty to protect their allergic children and for teaching their children's caretakers and other members of their social milieu how to use epinephrine. While using epinephrine might itself be considered a sign of a minor moral failure – proof that a mother mixed up the cow's milk and soy milk or failed to properly wash her children's hands – not using epinephrine and watching a child fall seriously ill or die is an even greater failure. Being a food allergy mom thus means inhabiting a frightening moral drama in which epinephrine has the power to save the day when all else fails. Their stories, of which Sarah's is a prime example, demonstrate the hazards that accompany a food allergic life and the role that epinephrine auto-injectors play in both allaying and signifying the risks of the job.

## Death Talk: Epinephrine as Savior

The specter of death from anaphylaxis is ubiquitous in the food allergy community, much as it is in Sarah's narration of her life with a child with food allergies. In her stories and in many, many others, epinephrine auto-injectors appear as miraculous saviors, rescuing innocent victims from death following an allergic reaction to food. I refer to these stories about death and death narrowly averted as "death talk." I learned this term from an informant with whom I became close during my research, and who continues to be part of my professional network. A trained social worker, her life revolved around food allergies: she had food allergies herself, wrote a self-help book about living as an adult with food allergies, and established a professional name for herself as a counselor for families and individuals struggling with new food allergy diagnoses. In explaining the idea to me, she expressed frustration that so much conversation in the food allergy advocacy community concerned the risk and fear of dying. For her, this stood in the way of *living* with food allergies. I consider "death talk" to be written and oral stories about people who die or come close to death as a result of unforeseen allergic reactions to foods. Death talk positions epinephrine auto-injectors as necessary, life-saving tools that mitigate the ever-present risk of anaphylaxis and death. They are positioned, to play on Hilgartner's (1992) coinage, de-risking objects. Death talk conveys lessons about the moral duty to protect those with food allergies by making and repeating the lesson concerning the necessity of epinephrine auto-injectors for preventing deaths due to food allergies.

I heard death talk everywhere in my research: in blog posts, in casual conversations, in lectures to parents and health care workers, and in interviews with patients and parents, including the interview with Sarah recounted previously. While food allergies can sometimes lead to the serious, multi-system allergic reaction called anaphylaxis, and while anaphylaxis can sometimes lead to death, death talk makes the argument that food allergy, anaphylaxis, and death are linked inevitably in all cases. The social worker who coined this term is not alone in her opinion about the counterproductive effects of death talk: other professionals in the food allergy world, including lawyers, professional advocacy staff, and those who speak about dealing with food allergies as adults, also try to focus more on living with allergies than on the fear of dying from them.

In online food allergy blogs, a popular entry point into the food allergy world, death talk abounds. Many of these blogs are written by mothers of food allergic kids who are the primary caretakers of their children. These women are almost universally white, and many have advanced degrees, such as JDs, Master's Degrees in education, or even PhDs. Many blog around full time jobs, but it is also common for food allergy mom bloggers to work only part time or to stay fully occupied at home, overseeing menu planning, meal preparation, and school activities to keep food-based allergens away from their children. Bloggers routinely post stories about close calls, in which they or their children eat a food which triggers an allergic reaction and leaves the individual wheezing, gasping for breath, projectile vomiting, becoming covered in hives, developing "clown lips," and fainting. In many of these stories, the allergic person is saved at the last minute by the (often delayed) administration of epinephrine via an epinephrine auto-injector. In a few, the person fails to receive an epinephrine injection or get to the hospital quickly enough and dies.

One blog post that exemplifies death talk appeared on the Allergy Eats! blog during the summer of 2014. Titled "Our First Experience With the Epi – All the Details and 16 Lessons to Take Away," the piece tells the story of what happened when the writer's teenage son eats a cookie with hidden nuts at a party (Antico 2014). (Unusually, the writer of this blog is the father of a food allergic child, not a mother.) At first, the son and parents don't believe the reaction is severe and treat it with Benadryl. Eventually the son senses that something is not quite right and the parents call 911 for an ambulance to take him to the hospital. In the end, it’s a good thing they did so: the reaction recurs hours later, to the surprise of both the family and the emergency room staff.

The “16 lessons” that punctuate the post are written in bold, italic text. Epinephrine turns up in eight of them. For example, lesson 2 states, “Teach your teens to carry their autoinjectors. Help them find a way to avoid any embarrassment they may feel.  Have them read this story if necessary.” Lesson 7 instructs the reader, “When you decide to use the epi, be strong in your conviction – you’re doing the right thing.  Don’t hesitate!” Lesson 8 exhorts, “The epi provides immediate relief, so use it!” It is echoed by Lesson 13: “Did I mention – Don’t Fear Using the Epi!  Fear NOT using it!” The writer ultimately credits the food allergy community with equipping him with knowledge about the importance of being prepared to us epinephrine auto-injectors:

> I have learned so much over the years reading and hearing about everyone else’s experiences – the right decisions and the wrong decisions.  **We are all in this together!** And if I hadn’t learned from you that giving an epi too late can be fatal, that epinephrine can’t harm your child, that the relief of an epi is virtually instantaneous, that getting an anaphylactic sufferer off his feet is important, that calling 911 after administering an epi is ‘mandatory,’ etc., well… thank you for teaching me! (Antico 2014)

The message of this post is clear: food allergies are dangerous and epinephrine auto-injectors protect the lives of people with food allergies. It is the shared moral duty of friends, family, and community to be prepared to use these devices to save lives in the event of food allergy emergencies.

A more unsettling example of death talk is a frequently updated blog post on the online support website No Nuts Moms Group (Rutter 2015). Titled “Remembering Those We Have Lost to Food Allergies,” the post consists of a list of names, arranged by the year of death, in bold, red text, followed by age, cause of death, and a link to a relevant online news article. This particular list includes both children and adults. A typical entry reads, ‘**Michael Saffioti,** 22, died from dairy allergy after eating oatmeal containing dairy.’ Another, from 2008, features more dramatic language: ‘**Daniel Sargent,** 30, collapsed after taking a bite of a chocolate chip cookie.’ The news stories to which these blogs link describe the events leading up to the person’s death, give some basic facts about the person’s life, and explain that food allergy is apparently on the rise in the United States. In the comments section (which had 41 posts in November 2015), some readers express their gratitude for the list, while others report that the list drove home for them the seriousness of food allergies. This list epitomizes the genre of death talk: these stories draw a straight line from a food allergy diagnosis, to allergen exposure leading to anaphylaxis, and then to death.

Death talk is not only a public genre. These stories are also passed from person to person. For example, during an interview with a nursing professional whom I will call Shelly, whose son has severe food allergies, she told me a detailed story about her son’s first anaphylactic reaction as a baby. Rather than administering epinephrine and taking him to the hospital, she gave him an oral antihistamine – an old mode of treatment that is no longer recommended for anaphylaxis, though it works for milder, environmental allergies – and monitored him closely for over a day. Already familiar with the signs and symptoms of medical crises from her training, she managed the superficial symptoms, like facial swelling, but began to worry when too many hours passed without her son producing urine, a sign of kidney failure. At this point Shelly began to regret her decision not to give epinephrine, which she had made because she wanted to avoid the hassle of a trip to the emergency room and because she had confidence in her ability to handle a medical emergency. Luckily, his condition reversed as soon as she began to worry; he peed and his other symptoms subsided. It was a close call, she emphasized, and she would not recommend that anyone else take the same course of action.

Why is there this emphasis on the nearness of death in the food allergy community? My experience in this community has taught me that *all* people who are interested enough in food allergies to seek out others with a shared diagnosis are interested in "educating" one another and the non-expert public about the "proper" management of food allergies. Most in the food allergy community believe that when people without food allergies understand the seriousness of an allergic reaction, they will take steps to keeping people with food allergies safe, such as refraining from eating in public or offering food to allergic kids. Consequently, a key goal of raising awareness about food allergies is to convince audiences that food allergy is, in fact, a serious medical condition. Food allergy writers seek to do so by connecting the dots, from a food allergy diagnosis to allergen exposure leading to anaphylaxis to death. By making audiences "more aware" of the dangers of food allergy and of the necessity to use epinephrine to reverse reactions, food allergy writers are also seeking to make them more responsible. If the message is properly conveyed, food allergy patients, parents, and advocates seem to assume, the public will be equipped with the practical tools and the moral sensibility to recognize and treat anaphylaxis using auto-injectors.

Death talk thus serves two normative moral purposes: first, to educate readers about the life-or-death stakes of food allergies; and second, to teach them how to responsibly care for people with food allergies. These stories show the worst case scenario – food allergy diagnosis leading to anaphylaxis leading to near-death or death – and suggest that this course of events is inevitable. Being prepared by carrying and using an epinephrine auto-injector is set up as the model for the morally proper behavior of a caretaker or a food allergy patient. Indeed, despite the significant financial consequences of an ER visit, epinephrine use is now positioned as the *first* step to take, no matter the apparent severity of the early stages of the reaction. This logic of preparedness often counteracts that of common sense, as the Allergy Eats! blog post demonstrates. In the context of the modern American health care system, the procedural mandates of death talk stories and epinephrine use put individuals and families in a difficult position, where the cost of medical care, the time spent going to and staying in the hospital, and the desire to protect life end up as competing priorities. Yet death talk takes this complex moral terrain and reduces it to a binary decision: use epinephrine and be responsible, or do not use epinephrine and be morally culpable for the bad outcome.

## ‘Morality’ as an Analytic Concept

Discussions about and use of epinephrine auto-injectors structure the moral sensibilities of the food allergy world. When patients are taught when and how to use epinephrine by their allergists in clinical encounters, they learn to enact a particular instantiation of biomedical preparedness logic in the event of a (potentially) lethal occurrence in the life of a person with a chronic disease. When parents highlight the tension between the cost of the devices and their duty to protect the lives of their children in food allergy blogs, they demonstrate how financial decisions are morally loaded. The “moral career” of allergy moms and the death talk that circulates in the social milieu of food allergy bloggers efforts embed the moral negotiations unique to managing food allergies within the general ethical concerns of parenting and the responsibility for sustaining a child’s life. The logic of biomedical preparedness, the financial and opportunity costs of healthcare, the duty to protect children, and the social milieu of illness activism: these are four important themes around which the moral world of the food allergy community revolves across contexts. Epinephrine auto-injectors are at the heart of negotiations in the food allergy community about what is "right" within each of these domains and about how to properly balance them when their mandates conflict.

At stake in the advocacy efforts of the food allergy community is an attempt to make what they understand to be the morally correct way to manage food allergies into what is socially "normal" in ordinary, non-allergic society. Broadening access to epinephrine through patient and caretaker education, among other things, would make food allergies part of normal social life, thereby normalizing food allergies and reducing its status as a social, biological, and personal "problem." It remains unclear if easy access to epinephrine should be right (for all) because it is normal (for some), or if it should be normal (for all) because it is right (for some). Chapter Six will examine the legislative advocacy surrounding this issue, but concern about the alignment between normal and right is salient in many aspects of life with food allergies.

The analytic conception of morality as something that is always-in-formation by way of discourse and practice does not discount the normative expectations for care held by the actors who inhabit the food allergy world. Their world – the world in which epinephrine's moral life unfolds – is bounded by normative rules inherited from their cultural situation as generally middle-class Americans who seek to live long, financially secure, physically safe lives. Saving lives, especially the lives of children, is a self-evident good for my interlocutors. Laidlaw (2014) suggests that one challenge faced by the anthropology of morality is to bring together the practice-oriented dimension of morality suggested by Bourdieu's *habitus* with moral philosophical concerns about the normative meaning of "the good". This chapter responds to his challenge, showing how, on the one hand, a normative moral order is established and deployed by members of the food allergy community as an advocacy tool, and on the other hand, how an approach to the moral informed by Goffman's relational understanding of the term reveals the contingencies (like biomedical knowledge and the financial arrangements of healthcare delivery) that shape what is considered morally correct. These two meanings of morality necessarily coexist in the lives of people living with food allergies.

Following how epinephrine auto-injectors are mobilized within the community via multiple discourses and practices illustrates one case of how things get used to communicate and enforce a normative moral order. The intention is not to document exhaustively the normative moral principles of the food allergy community, but to understand how objects, events, narratives, and certain social roles are animated with moral significance, in this case by way of their involvement with epinephrine auto-injectors. This understanding of the moral is deeply social, since it proceeds from the understanding that interests and identities are constructed via social interaction rather than absolute (biological, political, financial, ethical) truths waiting to be discovered. This internal moral order, as will be shown in the chapters that follow, motivates activist projects and sets the terms of political debate surrounding food allergies.

# CHAPTER 4

# PERSONALIZING RISK IN FOOD ALLERGY WORLDS

People with food allergies find themselves living constantly at risk of a reaction. Food residue on structures in public parks, hidden food ingredients in baked or processed foods, honest mistakes or attempts at subverting a loved one's diet: risky objects, spaces, and moments abound. In the food allergy world, there is therefore constant concern about understanding and mitigating the risks the world poses to allergic bodies. This chapter engages with the illness narratives (Kleinman 1988) of people with food allergies, or caring for food allergic children, to sketch a portrait of the risks encountered in embodied life in food allergy worlds. "Food allergy worlds," as introduced previously, is a play on Rapp and Ginsburg's (2012 Ginsburg and Rapp 2013) "disability worlds," a term they use to refer to living with and parenting children with disabilities. They use this term to draw attention to "how families mediate and rewrite kinship to accommodate their own intimate 'unnatural histories' that incorporate the experience of living with disability" (Rapp and Ginsburg 2012, 177). How to parent a child to prevent, reduce, or manage food allergies is similarly a prime concern for food allergy moms. How to parent as a person with food allergies – including mitigating the risk of passing along this dysfunctional biological legacy – and how to relate to other kin and friends come to the fore for food allergic adults.

People living with food allergies – both adult sufferers and parents of allergic children – remain constantly vigilant in order to mitigate risks to health and life in everyday life. One's position in relation to the disease – sufferer or witness – in part shapes what is deemed risky. Adults with food allergies know the risks posed by the condition in an embodied way. Anthropologists have argued in recent years that embodied experience informs culturally patterned decision making and social life (Csordas 1990). At the same time, how sensations are encountered and interpreted are shaped by cultural features such as moral codes, kinship, and social position (Geurts 2002). Complementing the ethnographic literature are a number of environmental historians who have demonstrated that experiencing the environment in an embodied way, especially through the sense of smell, has guided judgments about the safety or "health" of locales (Valencius 2002, Parr 2010). Sensation can be seen as both culturally informed and as the fodder for culturally-determined evaluations of risks to health. For adults with food allergies, embodied experience of illness and substances in their environments guides the choices they make about medical care, environmental exposure, and food consumption alongside expert biomedical discourse[6]. Sometimes this hybrid processes results in choices that are at odds with biomedical advice. By contrast, when parents witness their children living through allergic crises, they often hew more closely to the rules in order to protect their children. These decisions are ultimately ways to manage the existential risk that allergic sensitivity poses to life itself.

As discussed in the introduction, much existing social theory about risk is focused on the bureaucratic processes that help to determine "risk objects" (Hilgartner 1992) or the political responses to risk (Beck 1992; Douglas and Wildavsky 1982; Jasanoff 1990; Jasanoff and Kim 2009). Large-scale disaster preparedness efforts (Gusterson 2008; Lakoff 2008; Anderson 2010) have been another focal point of research, with a few analysts also concerned with the affective impact of such anticipatory activities (Masco 2008; Adams, Murphy, and Clarke 2009; Massumi

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[6] I do not see this as being quite the same issue as Wynne's (1992) and Epstein's (1995, 1996) discussions of the construction of "lay experts" or "lay expertise". The point of arguments about lay expertise seems to be to show how non-"experts" participate in the production of knowledge. What I am interested in here is how "expert" knowledge is domesticated, made part of everyday experience. This is also more about hybridization of ways of knowing the world than about non-experts adopting expert techniques and discourses. There is something to say about how food allergic adults and parents of allergic children participate in constructing biomedical knowledge about food allergies, but the evidence in this chapter does not speak to that issue.

2010). More recently, Sarah Lochlann Jain (2007, 2010, 2013) and Joseph Dumit (2012) have started to explore how individuals experience and enact risk in their personal encounters with biomedical knowledge. It is this last thread that is of particular concern in this chapter. In light of public debates about anticipation and preparedness, as well as the risk reduction paradigm that is currently central in modern biomedicine (Dumit 2012), I am interested in understanding how risk logic becomes domesticated, becoming part of intimate, everyday life.

People managing food allergies provide a prime example of the domestication of risk logics. They negotiate the seriousness of their symptoms in real time, weighing the health and social consequences of different treatment options even though such delays (not to mention some of the choices they eventually make) contravene medical wisdom. Past exposures, hereditary factors, and other proposed etiologies, as well as future calculations of risk, are refracted through these everyday experiences in or close to the present. Yet these factors (in both expert biomedical and patient epistemologies) influence the body in many, practically imperceptible moments over the course of a lifetime. The development of their affliction recalls the situation of women workers suffering from environmental illness in midcentury corporate America that Michelle Murphy (2006) documents. Detecting direct causation remains impossible, yet people living with food allergies seek to make sense of their situation using the information and culturally specific forms of reasoning they have at hand. Listening to the stories and theories at play in the food allergy community presents an opportunity to understand what it means to “live at risk”.

Everyday experiences recombine with cultural attitudes towards “the natural” and “the technological” to proliferate a rich set of etiological theories about the origins of food allergies. Frameworks like the hygiene hypothesis and theories about how early childhood exposure to common allergens and microorganisms may contribute to allergic disease suggest a variety of ways in which interactions between the cultural body and its natural surroundings trigger the condition. Adults living with food allergies and parents of allergic kids in the United States are constantly interrogating such biomedical theories of food allergy etiology to find *the* reason why and how their condition developed. In their reasoning, mainstream biomedical ideas often coexist with alternative theories that blame elements of the modern Western lifestyle for the misfortune of illness: the presence of pesticide residues in food, the rise of genetically modified organisms (GMOs) in Western agriculture, and the expansion of childhood vaccination regimens. At the root of both sets of ideas is a tension between the power of technoscience to cause and cure disease.

As previewed in the introduction, I argue that etiological questions are, in Mary Douglas' parlance, "forensic" questions that interrogate social organization at the same time that they seek material explanations for present misfortune (Douglas 1990, 1992). One forensic dimension of food allergy risk concerns the search for reasons why *I* am allergic and other people are not. This chapter examines examples of this logic and how it shapes preventive actions and responses to embodied signs of allergic reactions. A second part of the forensic impulse, to be addressed in the next chapter, searches for ways to root out and prevent contamination of food allergy-safe foods. Blame for food allergies is often assigned to elements of the modern American lifestyle. The things and events that get blamed reveal deep anxieties about essential elements of human life, both physical and social: wholesome food, safe shelter, and effective social institutions. Those explanations that seem to stem from the agential power of those affected, such as decisions about breastfeeding, are viewed, by contrast, with suspicion *because* they seem to assign blame to some of the very people most negatively impacted by food allergies – namely, mothers. Explanations that situate blame for the misfortune of disease outside of individuals, in the texture of society, become more plausible in the context of how risk is reckoned by those living with food allergies. How this reckoning proceeds will be explored in the second half of this chapter.

Ultimately, then, this chapter has two aims: to explore the experience of living "at risk" of an allergic reaction; and to examine how this lived experience becomes entangled with, and even challenges, forensic, biomedical theories about the origins of the condition. I offer an alternative way to understand the social life of technoscientific risk, one based in the perspective of patients and caretakers. Risk is "real" in the lives of contemporary patients, a discourse and set of practices in which they find themselves embedded from their first encounter with a physician (or even with Doctor Google). Attending to the way their illness narratives (Kleinman 1988; Mattingly 2014b) are suffused with both lived experience *and* expert biomedical knowledge reveals judgments about the risk of harm to be a personal, real-time, almost tangible force in their lives. Their stories show the extent to which the logic of risk is now deeply entrenched in everyday life in biomedical societies.

## "When You Live an Elimination Diet": Life as an Allergic Adult

> Me: If you could go back in time and talk to yourself a week after this diagnosis, what kind of advice would you give yourself?
>
> Michael: I would probably tell myself, use the EpiPen. It's real. That first year, I didn't use an EpiPen. I was scared of it, and I didn't think my reactions were bad enough, because you really couldn't see – I get a loss of blood pressure. My lips don't get massive, they get swollen. But I think I would've told myself, hey, this is really serious. Use the EpiPen… I came way too close to being dead way too many times.
>
> Me: That sounds really scary.
>
> Michael: You get used to it!
>
> Me: Really?!

> Michael: Yeah! It's this strange thing. Just like anything, you get used to… Driving… You know how it is to drive in New York. There's a certain way. People are going really fast and honking… and driving really close and it's really intense. If you come from some farm in Kansas and you go there, you're going to have to learn how to drive New York-style. Having anaphylaxis a lot, you have to learn. It's a different terrain. You have to learn how to navigate the terrain.

People living with food allergies, including food allergic adults like Michael (a pseudonym), engage in a tricky risk calculus when deciding how best to manage symptoms when they occur. Decisions are made through weighing bodily sensations in the moment, memories of previous reactions, and the social consequences of using or not using epinephrine in a particular situation. It is, as Michael points out above, a *learned* way of life. Symptoms that, on paper, indicate the systematic, potentially life-threatening allergic reaction called anaphylaxis and call for treatment with epinephrine are sometimes stoically ignored or treated with antihistamines instead.

Using epinephrine is no small event, as I learned firsthand in 2009. I had sought the services of an allergist for persistent stomach problems following meals that I thought might be due to a food allergy. Blood tests for common food allergens were inconclusive, but skin prick testing revealed a long list of environmental allergies. After a couple months of allergy shots followed by a few weeks off for holiday travel, my first shot in 2009 produced congestion in my sinuses. When I reported this symptom, the physician's assistant and one of the doctors on duty led me into an empty exam room and stuck me with a syringe of epinephrine similar to the dose of an epinephrine auto-injector. Already nervous following the to-do they had made about me in front of other patients, the epinephrine put my body and mind on high alert. My heart raced and my whole body turned pale and began sweating and shaking. My vision turned black around the edges and I screamed over and over again, resulting in a stern warning not to frighten the other patients. According to a small plastic monitor hooked on to my finger, my oxygen saturation level fell as a result of my outward physical response and the increased metabolic rate of every cell in my body. I was instructed to breath through a plastic tube that ran from my nose to an oxygen tank. I was not taken to the hospital (I would be in 2016), but I stayed in the office until 6:30pm, well after their normal 5pm end of business. I don't remember how I got home. I was weak and tired for two days afterward.

Avoiding the pharmaceutical big guns allows allergic adults to meet the obligations of the day. This is even more true now than when I experienced epinephrine in 2009, since treatment is now more likely to be followed up with monitoring in a hospital emergency room. According to biomedical doctrine, however, choosing not to use epinephrine is a life-threatening move. Anaphylaxis can lead to death; therefore, to lower the risk of death, epinephrine should be administered as soon as the condition is suspected. But in real life, risk is experienced in an embodied way, and its effects are understood to be social as well as biomedical. What to do about an allergic reaction is negotiable and sensitive to social life as well as to biomedical orthodoxy.

Michael has many responsibilities and expectations to balance. He is a young man living in a major city in the southeastern United States who was diagnosed with food allergies three years prior to our initial conversation. When we spoke, he was largely homebound. He had quit working years before because foods and other substances in the environment were triggering multiple anaphylactic reactions per week – as many as three per day, in his recollection. When I reached him by phone, he was putting his nine-month-old son down for a nap. He is in charge of childcare while his wife works full time to support the family. Given the disabling level of his allergies and the amount of time and effort that he had to put into finding, purchasing, and preparing safe foods, this arrangement was the only one that made sense.

Like many adults I spoke with, Michael has reactions to foods he ingests as well as to scents and “fumes” from allergenic foods and from manmade products in his environment. His environmental sensitivities developed concurrently with the food sensitivities. In our conversation, we shifted back and forth between talking about reactions to environmental factors and reactions to foods. For Michael, all reactions are experienced as a continuous part of the same disorder, regardless of the source. As we talked, I was struck by the way he wove metaphors about learning and habituation into the story of his personal experience. The allergic life was not something he chose to live, but it was something he had learned to deal with through trial and error during years of physical suffering. Learning to live this life of hair-trigger sensitivity to foods and the environment was such a singular experience that it could only be apprehended by an outsider through analogy. It was, as he described it in the opening quote, like learning to drive in New York City after living in Kansas all your life. The stakes were potentially life or death, though the ordinary settings and substances that provoked crisis were mundane.

As our interview quoted at the beginning of this chapter continued, Michael further elaborated on how he weighs the decision to use his EpiPen:

> Michael: The little charts they have, the “when to use your EpiPen”… When you have two systems that are going wonky, it’s anaphylaxis and you should use your EpiPen. But if I would’ve followed those charts, say, yesterday, I would’ve used two EpiPens, and this morning I would’ve used one. But I was used to the reactions, so I can say, oh, this one doesn’t feel like it’s going to go there. I got out of the situation. I smelled the fumes and I bolted and I got myself to a safe place.
>
> If you look at it like this: if it goes past a certain point, oh, then, take it seriously, use the EpiPen. But once you get used to it… You go on a hike. You have to learn how to hike. You have to learn where to put your feet and when to push harder and when to back off. And it’s the same sort of thing. Does that make any sense?
>
> Me: Yes, it does make sense. It’s almost like you’re describing a kind of intuition you’ve developed about what feels good, what feels bad – what feels safe and then maybe what feels dangerous.

> Michael: It's not intuition because it's based on hard facts, if that makes sense. It's like, oh, I've gotten to this feeling, this is happening. If THIS were to happen then for sure we're in a different league. But until that happens, you just can't make a chart. It doesn't work. You have to know it for yourself. It's like knowing when you're hungry or not. But it's not intuition. It really is grounded in, "oh, I went there once, and that was really bad … I didn't use the EpiPen at that point, and I should have, and when I didn't do that, this happened." So, it's a lot of "if, thens." It's all logical. At least to me.

Far from being unsystematic or capricious, Michael describes the decision tree for using an epinephrine auto-injector as a "logical" process, one that tries to square sensations experienced in the present with the memory of sensations in the past. In his view, sensations, despite being intensely personal, are also concrete and specific enough to be subject to logical decision-making. But the logic of sensing a reaction and squaring it with the past overrides the wisdom of the "little charts" provided by biomedical experts to guide decisions about when to use epinephrine. For Michael, embodied knowledge about what "safe" reactions feel like is more reliable than technical heuristics concerning the border between safety and danger. Assessing the risk posed by a reaction happens in real time through reference to sensation and memory.

Yet bodily knowledge only goes so far. His embodied calculations about the riskiness of a reaction only extend to reactions he feels in his own body. When it comes to caring for a baby with food allergies – another person whose sensations he cannot directly access, and one whom he also has a special responsibility to keep safe – embodied understanding gives way to biomedical procedure:

> Me: So I'm curious, how does some of that translate – or does it translate at all – to caring for a baby who you mention is developing some allergies… Can you use those same logical processes?
>
> Michael: No! It totally doesn't work. It only works for me, which is really weird. I'm looking at him and I can't feel inside of him. I can't. I have no way to know how he's feeling. But I guess what I did know is… It goes back to the chart. Two systems compromised and it's dangerous.

When it comes to caring for his son, the decision to use epinephrine is more straightforward. Here, "the chart" is useful. Meeting the heuristic of "two systems compromised," traditionally (though no longer) a distinguishing feature of an anaphylactic reaction, is enough to make a determination of danger. In this, Michael is also in line with the lessons of “death talk” discussed in Chapter Three, where anaphylaxis is equivalent to death and the only responsible course of action is to administer epinephrine. The responsibility to follow medical advice and to use epinephrine is compounded by the responsibility for parents to keep their children comfortable and safe. While his own allergic reactions can be parsed logically and thoughtfully, witnessing his son “scream and scream and scream and scream” is a call to action.

Michael gave many other examples of how living in an allergic body impacts social life. It is difficult for him to go shopping, go to synagogue, and visit with friends:

> Michael: I don’t have a social life. I can’t really go anywhere… Whenever I’m around people, I get anaphylactic reactions to the deodorant, or the perfume, or air freshener in commercial spaces. The synagogue sprays this junk in the air. It’s not realistic to go out. And restaurants are off-limits, too, not that we have a lot of fancy restaurants in [my city], but there’s a couple. The pizza place, forget it, it’s deadly, and there’s another place, a meat restaurant, that I probably have a 50/50 chance of getting sick when I go there – not to eat, just to be in the building. I don’t eat anything I don’t prepare.
>
> Me: That sounds like a pretty big change, then – I’m assuming [going] from a normal adult life to not being able to go out at all, not even being able to go to the synagogue as you were saying.
>
> Michael: Yeah, it turns everything on its head… I guess, you learn who your friends are, because when you don’t show up and they don’t come to visit, you kind of say like, oh, well this guy’s coming to visit and this guy’s coming to visit, or this guy’s bringing me food he grew in his garden. Then you know who really your friends are. And it’s interesting. It’s hard. The loneliness is definitely, definitely there. I make up for it to some extent online. I try to stay involved in online communities. If I didn’t have that, I would have completely lost my mind by now. That saved me.
>
> And going to the farmers market. It’s open air so I stand around and talk with a couple farmers. You would think that’s just incidental, but that’s actually my social outing for the week. We don’t really have people come over because their deodorants, perfumes makes it tricky. It’s hard when you invite someone over for a meal and you get sick. It’s hard to say, um, excuse me, you’re killing me, can you leave? It’s really kind of awkward!
>
> Me: I feel like there’s a romantic comedy there somehow.
>
> Michael: It’s absolutely hilarious! And we laugh all the time about it. But there’s also, you know, it’s also sad. It’s sad when there’s people that you can’t be around even if you want to because of their deodorant. And it’s hard. Some friends I can say, oh, stand downwind. You know they’re a good friend if you can tell your friend to stand downwind from you!

Through trial and error, Michael has learned what kinds of spaces (restaurants in general) and which specific places (a particular "meat restaurant" in his city) are risky, and what kinds of spaces are safe (his home and the open-air farmer's market). Having so many places off-limits severely restricts the possibility of socializing with old friends or even attending religious services. Both food residues and synthetic products like personal fragrances trigger illness for him, making not only *places* but also particular *people* potentially dangerous. There is a certain irony to the pattern of his reactions: the cleaning and personal products that symbolize cleanliness and health for ordinary people present a material danger to Michael's allergic body. It is only with the closest of friends that this aspect of his lived experience can even be disclosed, leading to comedic moments but producing an overarching aura of tragic loss. Michael's experience is typical of the stories I hear from adults with severe allergies, as well as for the parents of allergic kids who are trying to protect their children's health. In allergy worlds, social life responds to the demands of the body.

While interviews are one rich source of data for accessing embodied life with allergies, another source is the voluminous body of writing by food allergic adults and parents of food allergic kids, which documents how they have adapted to life with allergies. The memoir *Allergic to Life: My Battle for Survival, Courage, and Hope*, written by Kathryn Chastain Treat (2013) and based on her own journals, medical records, and legal documents, provides an especially vivid record of life with allergies. Treat opens the book by describing her quite ordinary middle class life: she is a baby boomer, born in 1954, an older sister, a wife, a stay-at-home mom when her kids are young, and a PTA member. Despite a diagnosis of asthma, she had always been quite healthy prior to developing allergies as a middle-aged adult. In 1999, as her kids near adulthood, she goes back to work as a secretary at the local school district where an environmental exposure seems to trigger a long list of allergies to foods and environmental substances. The decision to return to work, she writes, is "*the beginning of the end*" (Treat 2013, 1; emphasis in original).

Weeks into her new job, Treat begins to suffer from sinus pain and pressure. Reluctant to take time off work, she visits a local urgent care center, receives a diagnosis of a sinus infection, and begins taking broad-spectrum antibiotics. But the infection doesn't go away. Her ear, nose, and throat (ENT) doctor eventually determines that she has a fungal infection, likely picked up from her new office which has an odd "smell" and poor ventilation. Tests confirm the presence of low levels of mold spores in the space. Treat goes through multiple rounds of antibiotics – including medicines of last resort like amphotericin-B, called "ampho-terrible" by doctors for its toxic effects on many patients – and undergoes several sinus surgeries to remove pockets of infection and scar tissue. The infection is eventually checked, though it periodically rebounds. As it is brought under control, however, Treat begins to develop allergies and sensitivities to a wide range of drugs, foods, molds, pollens and chemicals.

On Valentine's Day 2001, Treat has a reaction to an antibiotic that is the archetype for her future reactions to drugs, foods, and other substances in the environment. She walks readers through her symptoms and her interaction with an emergency room doctor on that day:

> Rick [my husband] and I had made no definite plans on how we would spend the evening because I had been so tired, and we were not sure if I would feel up to anything at the end of the day. Shortly around noon, my throat began to feel restricted. I tried to wait it out. Finally I phoned Dr. D. He suggested that I go to the emergency room. I drove myself to the hospital, which, I realize now, was probably not the smartest thing to do …
>
> [At the hospital t]he constriction in my throat began to get worse and I was beginning to have tremors. My face felt like it was being pulled apart. The ER doctor came in. I told him – in between spasms in my throat and face – that I was having an allergic reaction to one or more of the medications that I was taking …
>
> The ER doctor had the gall to tell me that my reactions were not typical of allergic reactions. I was just having an anxiety attack. … Rick explained to the doctor that I had experienced many allergic reactions and that this was typical of the way my body handled them. His remarks fell on deaf ears (45).

The reaction recurs the following day:

> That morning I phoned in sick to work and just rested. … Some of the same symptoms began while we were working on the soup. My throat began to get tight and feel constricted. … By the time we reached [Dr. D's] office, I was beginning to have tremors. …
>
> The tremors and spasms in my face and neck continued to get worse. This time, however, I also began to have tremors on the right side of my body. My right hand and leg would shake. During the spasms in my neck, I had difficulty breathing. The doctor's staff would ask me questions. I would not answer right away so they would ask me again. I had no control over my body. I had to wait for the tremors and spasms to stop to answer questions. It was [as] if I were riding a wave. I would have a spasm and tremors and then it would stop, only to start up again within seconds. It was almost like a seizure. (46-47)

Treat's symptoms in this passage are dramatic. They go well beyond the most common symptoms of anaphylaxis, which include hives, redness, swelling of the mouth and lips, vomiting and diarrhea, and discomfort or difficulty breathing. Her reactions begin with a typical complaint of throat constriction, but the tremors and spasms that she describes are not among the symptoms physicians are typically trained to identify as indications of anaphylaxis. Drawing on such training, the ER doctor tells her that her symptoms indicate an anxiety attack, challenging Treat's understanding of her experience and downplaying the seriousness of her condition. Dr. D and his staff show more sympathy when she arrives at their office the second day, even though her physical state makes it impossible for her to be a model patient. There, her risk of serious harm is taken seriously. She is sent again to the ER, this time with advanced orders from Dr. D that she be admitted. Other physicians are called in to consult, and she is sent for another surgery two days later. This time her hunch that something wrong was taken seriously; in addition to managing her drug reaction, evidence of scarring resulting from her infection was found and she was treated accordingly by doctors familiar with her history.

At this point in her story, Treat is just beginning to learn which symptoms indicate an allergic reaction and what to do when they occur. Unlike Michael, who now weighs courses of action based on three years of experience, Treat calls her doctor for advice during this early episode. She brings us into the moment with vivid descriptions of sensations, movements of her body, reports of interactions with her doctors and husband, and metaphors to help communicate her perception of the events. Over time, she becomes more skillful at explaining the meaning of her symptoms to skeptical physicians, more judicious about using medications to slow or stop the reaction as soon as symptoms begin, and more assertive about avoiding spaces and activities that bring on reactions. By 2013, her medical team includes a mold expert at Stanford, several otolaryngologists in two states, anesthesiologists who accommodate her desire to use acupuncture rather than drugs, and an alternative medical provider named Dr. Rea who runs a center in Texas for people (mostly women) with severe allergies and environmental sensitivities. She freely mixes techniques from allopathic and alternative medicine to manage her reactions, carrying an epinephrine auto-injector in a lunch cooler that also contains homeopathic rescue medications, while taking daily high-dose antibiotics via an IV line, or undergoing major abdominal surgery while knocked out by acupuncture. She learns how to gauge and communicate her risk status in the moment, something she initially struggles with. She learns to act upon her bodily sensations and enlist others to help her, sometimes walking them through how to use her medications on the spot and other times bringing caretakers along with her to potentially dangerous locations. In short, she learns how to make her embodied feeling of danger intelligible to others.

Michael and Kathryn Treat are far from alone in providing detailed descriptions of the experience of being in the world in an allergic body, though they each present their experiences with exceptional coherence and narrative momentum. During food allergic adult support group phone calls that I attended for several months at the invitation of the group organizer, for example, participants often describe their symptoms in striking detail. We (for I am an active participant in these calls) talk about our skin – the patches of hives that erupt after eating, the acne that makes middle-aged women feel like teenagers, the swollen “clown lips” we’ve all had at one time or another – and our digestive complaints – how bloated and gassy we feel, how diarrhea has us speeding home from dinners at restaurants, how even a cup of tea can trigger convulsive vomiting sessions that leave us lying on the kitchen floor with the trash can within arm’s reach. We search for metaphors and analogies to describe the lethargy we feel after these “bad days” when we stay in bed for hours or, if life allows, days on end. Living in a body that reacts yields a singular experience, but discussing such bodily woes allows adult allergy sufferers to find common ground with each other.

Sharing these experiences – in online support forums, in written texts, and in real-time conversations – provides a way to communicate and calibrate individual understandings of the risk posed by food allergies. Delays in or avoidance of epinephrine administration, which read to medical professionals as treatment noncompliance, is part of everyday life. So are symptom profiles that are shared in detail or through the use of rich metaphors. *All* adults with food allergies make judgment calls about risk that are informed by their own sensations and experiences, no matter how confidently they can recite the medical recommendations and no matter how often they exhort others to follow them. When it comes to caring for another, medical recommendations are recalled and followed to the letter. But when it comes to themselves, what allergic adults know through embodied experience overruns what biomedical expertise can account for. Listening to their stories shows that this is less a matter of lacking faith in medical recommendations than a careful weighing of how to carry on with adult life while living at risk of allergic reactions.

## The Machine in the Garden: Theorizing a Lifestyle Etiology

In addition to taking practical steps to detect and mitigate food- and environment-based risks to their allergic bodies, people living with food allergies – parents of allergic children and adult sufferers alike – search for reasons why they developed the condition in the first place. What factors or forces put certain human bodies at risk of allergic sensitivity? These questions of epidemiology and etiology are, at their core, forensic questions about the sources of misfortune, akin to the forensic questions Douglas (1990, 1992) and Laidlaw (2010) highlight in their reinterpretations of classic anthropological theory. In the food allergy community, everyone from expert biomedical scientists to food allergic adults to full-time allergy moms are engaged in proposing, popularizing, and debating the sources of the so-called food allergy epidemic. The theories in play reveal a latent tension between a commitment to modern, technoscientific modes of making, doing, and knowing and nostalgia for utopian visions of the healthful, natural past. This is, in Leo Marx's (2000) telling, a distinctly American attitude toward technology that has underwritten national ideals of progress and possibility since the early seventeenth century. In the case of food allergy etiology, the question is, to what extent is allergy attributable to the artifice of modern life disrupting the nature of the human body?

The non-scientist members of the food allergy community whom I interviewed for this project believe scientific explanations to be generally credible. My interlocutors endure the frequent doctor's visits (for themselves or as chaperones to their children) and encounter reinforcements of scientific thinking about food allergies regularly via webinars, messages posted by physicians to social media, and listservs. These sources of information structure what they know about the condition, producing a high level of knowledge among non-scientists in the community about the scientific theories of allergies. Many are not convinced that doctors and scientists have *all* the answers, but to reject scientific explanations wholesale would invite skepticism and even ostracism from others in the food allergy community.

Discipline is swift when community members undermine scientific authority. For example, at one advocacy-centered conference I attended in November 2015, speakers repeatedly disparaged social media users who downplayed the need to respond promptly to the recall of Sanofi's Auvi-Q device. The recall withdrew all devices on the market due to potentially inaccurate dosing and undermined trust in the company, as described in the previous chapter. The device may never return to the market. Contravening techno-bureaucratic-scientific recommendations in public is understood to have the potential to undermine the seriousness of the community's credibility, thereby giving food allergy skeptics a new reason to ignore concerns about food allergies. Publicly recommending subversion of FDA recommendations was "dangerous" both to patients who might use a faulty device and to the community's interests. However, that doesn't mean that non-mainstream biomedical theories are dismissed out of hand or ignored completely. What is more common among my interlocutors is to recombine scientific theories with alternative theories (much as Kathryn Treat described doing in her memoir), producing hybrids that express deep skepticism about the modern American food system, medical progress narratives, and other aspects of modern life.

Many of the adults with food allergies I have encountered also have environmental allergies, sensitivities, or other autoimmune conditions, much like Michael and Kathryn. Their questions about where their allergies come from concern the biological mechanisms that produce food allergies as well as the causal relationship between food allergies and other allergic and immune system disorders. One such interlocutor is Jenna, a woman in her thirties who leads a Facebook support group and weekly networking phone call for food allergic adults. In addition to this community-building work, she has channeled her personal experience with multiple, severe food allergies into a consulting practice for training restaurants how to accommodate eaters with allergies and other dietary restrictions and training others to provide similar consultations. Jenna’s food allergies appeared in adulthood, after several bouts of acute autoimmune disease as a young adult, which led to two kidney transplants. Today, her food allergies number in the dozens, severely restricting her diet. Yet you would never suspect her history of serious illness when meeting her in person; she is sprightly and always smiling with long, wavy brown hair, full of stories about her childhood spent on a Native American reservation and commercial farm.

I first heard of Jenna’s work on Twitter. Following an email exchange, she invited me to participate in an in-person support group meeting for adults with food allergies at a national food allergy conference in the summer of 2014. Providing a support forum for food allergic adults is important to her because so much of the community’s focus is on providing support to parents of food allergic children. These groups often fail to address the needs of adults who are less concerned with navigating school bureaucracies and playgrounds and more concerned with managing meals with colleagues, dating, and overcoming fatigue while trying to contribute to their household’s financial health. The focus on parents and children is particularly strong at food allergy educational events, so providing a safe space for adults at this national conference was, in her view, sorely needed.

She explained these motivations to me during a phone interview after the conference, and also gave an account of when she developed allergies and how they had affected her family life, social life, and professional life. As the conversation continued, we began to discuss where food allergies come from and why some people develop them while others seem immune. Jenna turned out to have a highly elaborated theory of food allergy etiology that I continued to learn about over subsequent months of conversations with her. During our first interview, she provided a succinct introduction to her perspective, saying:

> One theory is the hygiene hypothesis. People are like, well, people are over clean. But I'm like, ok, time out, let me stop you right there. I grew up on a farm. I grew up in the middle of agriculture. I picked fruits and vegetables. I've eaten dirt. I have had well water, I've had tap water. I lived with cats and dogs and animals and goats and chickens and sheep and horses. I've been in wheat fields and strawberry fields, the whole nine yards. So hygiene, you know… While we cleaned up and washed our hands at the end of every day or when we came inside, I just don't buy into that theory. At all.
>
> I think I became more hygiene conscientious when my daughter was born, which was 12 years ago, or my son …. My son, here's another example, another reason why I don't buy into that. My son was born in the same hospital as I was, one floor apart. He spent the first few months of his life on the same farm, on the same ranch, that I grew up on. And then later on in life we went to live in the city and live the city life. But he just developed food allergies. He just developed food allergies and seasonal and environmental allergies. And he's sixteen. His body changed and he developed them for the first time in his life. So while he's still technically a child, he's an adolescent. Late onset as well.
>
> And my daughter who was born in Denver, born in the city, not raised on a farm, though she went to the farm later on, but has been a city girl her whole life, has no food allergies. None whatsoever. Not even a little. Not seasonal allergies, not environmental allergies, no food allergies, nothing.
>
> So I totally don't buy that theory.
>
> I talk to adults and a lot of the adults that I talk to have very similar experiences. They were raised in rural areas or in farming with dirt and worms. They weren't city kids necessarily, not that they were all farm country kids. And some of them still do! Some of them still live in rural America and don't have… they're not living in hospitals. And not that that's very sanitary either. But anyway. So that theory is out for me. I want them to abolish that.

Jenna had an encyclopedic knowledge of the various theories promulgated by scientists and lay people about the etiology of allergic conditions. She went on to explain the theories that immunizations, pesticides, the reduction of certain foods in the American food supply, or a lack of breastfeeding cause allergies. As with her assessment of the hygiene hypothesis, she used evidence from her own life to undermine each one. She had been immunized, as had immunized both of her children, but they all had different allergy profiles, weakening the case that vaccines cause allergies; she hadn't breastfed consistently but only one of her kids had food allergies, which eroded the credibility of American Academy of Pediatrics (AAP) guidance on breastfeeding and food allergies; and so on.

Her pet theory was that there was a causal link between allergies and other autoimmune disorders. She believed more scientific research would uncover further support for this link. She found evidence for this theory in her own experience as a patient and as a leader of support groups for allergic adults, in both cases noting a strong association between autoimmune disorders and allergies. In food allergic adult support group conversations, she reminded participants facing skepticism about their food allergies from colleagues and friends that their condition was autoimmune in nature, with scientific evidence for this ontological identity to come in the near future. This theory fit so perfectly with her experience and with the experience of the other adults with allergies that she talked to on a regular basis (mostly women, many with autoimmune conditions as well as allergies) that it seemed to be the most plausible to her. Orthodox or not, if a theory didn’t square with her own history and embodied experience of the condition, it was not plausible to her; if it did fit, then she might be convinced of its validity.

Like many food allergic adults (as well as food allergy parents), Jenna was willing to consider new information about allergy etiology. In another conversation about a month later, she shared some new suspicions about potential links between GMOs, the American food system, geography, and allergic etiology. She implicated changes in food production, such as the shift from traditional agriculture to high-tech production techniques, exemplified by hydroponically-grown tomatoes. A particular risk, in her revised view, was the consumption of genetically-modified organisms (GMOs). Many in the food allergy community view these components of the food supply with suspicion, and at least one mother has written a book that discussed the dangers posed by GMOs (O’Brien 2009). Through reading and reflecting upon information available online, Jenna had made an analogical link between the genetic modifications in foods and the potential for genetic instability in human bodies. The novel characteristics of these foods, she explained, means that human bodies no longer “know what to do with foods anymore,” and are “genetically modifying themselves” to keep up. Changing the compositions of some foods via genetic modification could, she asserted, change how human bodies processed *all* foods. Compounding the effects of these novel foodstuffs was the fact that her own body and the bodies of many food allergic adults she talked to were under stress because of the geographic demands of the contemporary labor market – specifically, the fact that adults must often move from one region to another for work. “We’re humans,” she said, “and our bodies adapt, and they change, and they are improvising.” These improvisations were not necessarily always good; they could lead to food allergies.

Geographic instability, genetic novelty, and high-tech food production: according to Jenna, these features of modern life in the United States destabilize the human body, leaving it vulnerable to developing allergic sensitivity. But this is not exactly a question of policing the natural/unnatural boundary, or of advocating for a more “natural” lifestyle. Indeed, in this exchange Jenna conceded the irony that eating with food allergies often means eating *more* processed foods and *fewer* whole foods – foods that are typically associated with “naturalness” – because whole food staples like wheat flour, legumes, eggs, milk, and raw nuts are some of the most common allergens. Foods that are marketed as “allergy-friendly” typically substitute complex mixtures of highly refined flours (often including buckwheat flour, potato flour, and tapioca starch to mimic the stickiness of gluten) for wheat flours, mixtures of refined starches and oils to replicate the binding properties of eggs, and specialized oil mixtures with factory-produced flavorings and, sometimes, spectacular yellow-orange coloring to replace cheese. They are not the sort of foods you would find at a farmer's market – although as Michael's experience illustrates, careful selection of whole foods at health food and farmer's markets is also a potential solution for eating safely for food allergies. For adults with food allergies on the go, the highly processed options are frequently necessary to balance health and the responsibilities of family and work.

Jenna's theory is a theory of the body's fragility in the face of rapid material changes: moving from one place to another, eating foods with different genetic makeups, eating foods produced in ways that might otherwise change their compositions. Her explanations reflect an understanding that food and environment have agential properties, exerting influence on the human body to change its response to material encounters with the non-self world (Valencius 2002; Murphy 2006; Mitman 2007; Nash 2007). Though Jenna's views on allergic etiology are particularly well elaborated into a theory composed of multiple interlocking pieces, the strategies she uses to decide what to believe and what to discard are typical of the food allergic adults I interviewed in the course of my research.

Jenna is not alone in her concern about how the American food system, and GMOs in particular, may be contributing to growing rates of allergic disease. Writer and food systems activist Robyn O'Brien is the most vocal proponent of a connection between GMOs in the food system and the increasing rate of food allergies in the United States. According to her book and public speeches I attended at food allergy conferences in 2014 and 2015, O'Brien began her professional life as an equities analyst, setting up nine-figure investment deals and directing business strategy decisions. Eventually she left the corporate world to have four children, bringing the same type-A fervor that got her through business school and into a prestigious career to child-rearing. When her youngest, a girl named Tory, reacted one day at family breakfast after having her first taste of eggs, O'Brien set out to discover what initiated her daughter's suffering.

Modern food quickly catches O'Brien's attention in her search for a culprit. "What had changed," she asked, "in our food to make it suddenly so toxic to our children? … When had food – one of the most immediate, personal ways I knew to sustain my kids – become so friggin' *dangerous*?" (O'Brien 2009, 1-2). O'Brien invites her readers to see her as an objective commentator, explaining that pointing the finger at industrial food production was particularly upsetting because she "believed in our system and its leaders," believing in their ability to make decisions that are both profitable *and* ethical (3). Before long, she comes across the work of two controversial alternative diet gurus: Kenneth Bock, whose writing and clinical guidance links the "toxic food supply" to a variety of health problems, including asthma, autism, allergies, ADHD, and other behavioral problems, and Joel Fuhrman, who warns parents that "the shift to "fake food" has actually altered our immune system," triggering the allergy epidemic (46).

As she becomes immersed in food system research and food allergy activism, O'Brien is upset to learn about the laxity of American food standards, including the FDA's allowance of artificial colors like Yellow Number 5 that are banned in other countries and the lack of labeling disclosing GMO ingredients. She concludes that the entire system – the rules and rulemakers alike – has been corrupted by food industry actors. As a result of their influence, she argues, consumers are uninformed: research findings suggesting detrimental health effects of GMO corn and soy, the dangers of growth hormones in milk, and the multifaceted effects that the polluted food system can have on children's bodies and development are all suppressed, O'Brien believes, as a result of industry pressure. Even groups that ought to represent the interests of patients aren't immune, she suggests, when she traces financial support for the patient-centered non-profit Food Allergy and Anaphylaxis Network (FAAN, now part of Food Allergy Research and Education (FARE)) back to Kraft and Dura Pharmaceuticals, and, more recently, funding for academic research on the etiology of peanut allergy back to the American industry group, the National Peanut Board (O'Brien 2009, 2015). The complexity and industry power in the modern American food system, in O'Brien's view, poses a plethora of undisclosed dangers to children and produces biased science. The improvements she observes in her daughter and three sons when she removes these dangerous, ultra-modern elements from their diets both motivates her research and supports her conclusions.

In some ways the perspectives of Jenna and Robyn O'Brien are in line with what Roberta Raffaeta finds in her ethnography of Italian allergy sufferers: narratives suffused with nostalgia for a pre-modern mode of life. She finds that Italian allergy patients who consult complementary and alternative medicine (CAM) specialists for their allergies are concerned, first and foremost, with the "naturalness" of treatment options (2013). For several patients who she quotes, the unnatural, polluted landscapes of the post-World War II era Italian landscape are assumed to contribute to the etiology of allergy. Raffaeta argues that "naturalness is a crucial concept in Italian discourses on health," a positive value in many contexts of health, personal appearance, and grooming (136). How the patients she interviewed talk about naturalness in allergy treatment is a microcosm of this broader moral order of health and healing. She positions the average allergy patient's concerns about "naturalness" as opposed to and ignored by the biomedical establishment, a fact which drives many allergy sufferers to CAM practitioners in the first place.

Though my American interlocutors share the worry that modern life (especially modern food) is implicated in allergy, the attitudes among my interlocutors in the United States also differ in some key respects from these Italian allergy patients. The most vocal participants in the food allergy advocacy world are well versed in the biomedical doctrine on allergy and deeply faithful to its promise to find a cure for allergic illnesses. Skepticism about modernity is less of a blanket assessment of the polluted nature of modern life and more of a forensic project to determine (and ameliorate) *those specific elements* of modern life that trigger hereditarily susceptible bodies to become allergic. Rather than seeking a return to a lost, pre-industrial state of purity, different camps among both experts and patients blame (singly or in combination) GMOs, pesticides, and food processing, which expose the population to more hidden ingredients than ever before, as well as maternal exposures to commonly allergenic foods, early childhood exposure to antibiotics, and environmental exposures to foods and/or pets during childhood. The link between "naturalness" and safety is also complicated by the profile of foods which people are commonly allergic to in the United States: the most common allergens include milk, soy, eggs, and wheat, the building blocks of many simple, whole, organic foods. So while modern life may set up the conditions under which an allergy "epidemic" can be spawned, there is no immediate, universal solution to be found by returning to a simpler, pastoral way of life for the majority of my American participants. Indeed, the machine has always been present in the garden in the American pastoral mode (Marx 2000).

One further example helps drive this point home. Canadian food allergy mother Heather Fraser (2011) wrote a volume called *The Peanut Allergy Epidemic: What's Causing It and How to Stop It*. The book is well known within the food allergy community but inspires a good deal of skepticism because of Fraser's suspicion of biomedical protocols. Fraser argues that vaccinations are *the* overlooked cause of the rapid acceleration of peanut allergy incidence beginning around 1990. The method of her book is to catalogue biomedical etiological theories and point out that, in her understanding, none could be seen as identifying the root cause of the increase in food allergies, given the *timing* of that increase. What rankles her in particular is the hygiene hypothesis, the idea that immune responses are misdirected due to a lower disease burden in many modern populations. The problem for Fraser is that “the hygiene hypothesis did not offer a purpose for allergy.… In positing that homeostasis was impossible without a burden of disease, the hygiene hypothesis gave little credit to the human body.” Her alternative: “perhaps technology and its concomitant toxicities deserve a closer look” (Fraser 2011, 64).

For Fraser, the “toxicities” that explain the circa-1990 inflection point that she identifies in peanut allergy diagnoses include a number of vaccines and their component ingredients, fungal overgrowth in the body, unhealthy diets, castor oil supplements given to newborns, and the use of peanut oil in foods, medications, and cosmetics. But her particular target is the *Haemophilus influenzae* type b (Hib) bacteria vaccine. According to the US Centers for Disease Control and Prevention (CDC), Hib is administered to infants and young children beginning around 2 months of age to prevent a potential disabling or fatal bacterial infection (Centers for Disease Control and Prevention 2014). Healthy scientific debate about the possibility that the Hib vaccine is a key factor in triggering peanut allergy, Fraser argues, “was sidelined by a new and all-encompassing concept of allergy and immunity – the Th1/Th2 paradigm” (35).

Nowhere in Fraser’s book is there a call for reversion to a utopian pastoralism. There is deep mistrust of current medical guidance in her analysis of the upward trend in peanut allergy, to be sure. The history of association between vaccine adjuvants, such as thimerosal, and unexpected immune responses to substances including peanut oil and cottonseed oil, serves as a warning – a series of precedents in which she believes detectable risks were downplayed, which justifies her distrust of current vaccination recommendations. But nature does not offer the way out. The flaw on the part of physicians and scientists is not simply that medical science has fostered an acceleration of technological sophistication. Rather, their shortcomings consist of ignoring particular pieces of evidence, especially evidence supporting the possibility that their own technologies are a potential cause. The solution, Fraser suggests, is that scientists should become *better at science*: better at suspending their disbelief to test out new ideas that contradict current models and best practices.

Both allergic adults and parents of allergic children are constantly navigating a sea of theories about what causes food allergies. Their narratives weave together personal experience and scientific theories in the search for answers to the question, “why me?” In patient and caretaker narratives, the immediate experience of life with food allergies serves as a litmus test for the credibility of biomedical theories of food allergy etiology. Scientific dictums that don’t align with personal experience are viewed with suspicion or discredited. But this is not a simple story of striving for a purer, simpler past to heal the harms inflicted by the decadent present. Allergies to common foods and an underlying, characteristically American, faith in scientific progress foreclose this easy solution. Instead, people living with food allergy trade in hybrid theories where the modern and the pastoral, and the individual and the statistical, comingle. A tendency to form such hybrids is, in the view of Bruno Latour (1993), characteristic of contemporary scientific expertise.

## Mother Blame

The refraction of biomedical theories of food allergy etiology through individual illness narratives that I encountered in the food allergy community begged questions about whether anyone could be held personally responsible for the disease. Many mothers in particular carried around guilt and self-blame for a child’s food allergic condition. The anxiety caused by managing their child’s potentially dangerous chronic condition was further stoked by changing recommendations from pediatricians and allergists concerning the proper method and timing of childhood food introduction for diminishing the chances of developing food allergies, asthma, and other allergies later in life. Eating is a fundamental need of young children (indeed, of everyone); it is also an activity that is heavily subjected to expert biomedical analysis and guidance. Failure to provide proper nutrition by failing to follow recommendations risks moral and even legal sanctions for faulty mothering. Yet feeding guidelines related to food allergies have been completely reversed in recent years, meaning that what may have been "correct" with an older child is now "wrong" – constituting ideal conditions for generating doubt and blame.

At stake in mothers' anxiety about shifting feeding advice is a question of agency (Jain 2006; Laidlaw 2010). If a mother's actions harmed her child without her knowledge, is she morally culpable? Should the blame be placed on biomedical experts who steered her choices about breastfeeding and food introduction? More specifically, how does the assignment of such responsibility affect life in food allergy worlds? The question of mother blame in food allergy worlds is an instance of a larger problem in Western societies. As feminist scholar Linda Blum points out, "the mother-valor/mother-blame binary serves, in modern Western cultures, to hold mothers responsible for child outcomes and thus for the health of families, future citizens, and the nation" (Blum 2007, 202). Food allergy mothers feel the contradictory pull of this binary distinctly: on the one hand, they willingly engage in heroic sacrifice of self-identity and career to care for their food allergic children; on the other, science and society alike hold them responsible for producing weak or finicky children.

Feminist historians and cultural theorists strongly critique the subjective effects of gendered care work upon the women who are expected to do it. Ruth Schwartz Cowan, for example, points out that rising expectations of cleanliness and technical proficiency created impossible expectations for mothers. The popular hygienic ideals “heightened the emotional context of the work,” making an impeccably clean home a signifier of a morally and socially upright woman (Cowan 1976, 23). Taking one wrong step was widely acknowledged to produce feelings of guilt – guilt that could then be treated with another new post-war technology, the tranquilizer pill to restore a woman’s easy demeanor in the face of unending, morally treacherous work (Metzl 2003). More recent analyses of “mother guilt” note that it can be particularly acute for mothers of children with chronic illnesses or disabilities (Rapp 2001, Blum 2007, Mattingly 2014a).

The breastfeeding hypothesis of allergic development is a prime driver of anxiety for food allergy mothers. Beginning in the 1980s, several studies reported that food-derived proteins could also be transferred via breast milk, raising concerns that a child could develop allergies to milk, egg, or peanuts through consuming the breast milk of a woman who eats those foods (Cant et al. 1985; Sorva and Mlkinen-Kilijunen 1994; Vadas et al. 2001). Recommendations from the American Academy of Pediatrics (AAP) followed, suggesting that mothers might change their diets by omitting common allergens to prevent their children from developing food allergies. Following further research which contravened these findings (Lack et al. 2003), and unwilling to add to mothers’ already considerable anxieties about choosing how to feed their newborns, a report by the American College of Asthma, Allergy and Immunology (AAAAI), the leading allergy research organization in the United States, issued new guidance in 2008 regarding maternal diet during pregnancy and lactation (Greer et al. 2008). In this updated view, the evidence supporting the inclusion or omission of common allergens in maternal diets in order to prevent food allergies was deemed “insufficient on which to draw more general conclusions”

(Fleischer et al. 2013). Medical science no longer warranted controlling the diet of pregnant and breastfeeding women as an acceptable intervention for slowing the rise in rates of food allergy.

The problem that several mothers I interviewed had with this theory was that it seemed to lay the blame for their child's allergic status at their feet. Many of them had breastfed while dietary restrictions were recommended. As one mother explained to me, the post-partum period is a difficult time for many women, one when a woman must learn to balance competing demands from family, career, social life, and baby, as well as physical and emotional recovery from childbirth. This informant emphasized that breastfeeding is difficult enough to fit into this constellation of responsibilities, especially if the baby turns out to be an unenthusiastic feeder, if the woman is expected to return to work quickly, or if complications arise during or after childbirth. To then be told that the way she does it is incorrect is hard news to face. A second mother who talked about this issue with me, who I will call Joan, explained to me in an interview her frustration with the breastfeeding theory:

> Joan: Well you know what, to be perfectly honest, [the idea that allergens in breast milk can lead to allergies] is not part of my thinking, and I'll tell you why. Because, as a parent, we feel guilty for everything. Oh my gosh. I must have done this to her somehow. And the theories on that particular theory change so frequently and really do a 180.
>
> When I was pregnant and breastfeeding, I did not avoid any foods. And so there was this thinking for a long time that I might have quote-unquote caused her to become allergic by having her ingest those foods *in utero* and then through breast milk. And then the theory switched 180 and they were telling mothers, pregnant mothers and nursing mothers, you know what? Maybe if you eat these foods, you'll desensitize your kid and they *won't* have food allergies.
>
> So the pendulum swung back and forth so drastically that I just decided to not listen to any of that, because that doesn't help my family personally. That might help future families in future generations, but I'm going to wait to see where they end up on that before my daughter talks about getting pregnant or, you know, having kids and breastfeeding. She can worry about where the current science lies then in, God-willing, ten to fifteen years, because between now and then it's going to change so many times that it can't help her. And it's only going to make me feel guilty or not feel guilty. So I just choose not to even focus on it.

Joan's experience of parenting included feeling guilty for things that went wrong with her child. Joan was an accomplished lawyer who worked in large law firms in a major US city both before and after giving birth to her children. She liked to have control over her life and the lives of her children. For her, buying into the idea that her careful choices about diet and breastfeeding ended up harming rather than helping by triggering food allergies in her kids would have added to her general feelings of guilt. In addition, scientific wisdom about the role of maternal diet and breastfeeding did “a 180” during the time her children were living at home. Such instability in what medical professionals regarded as fact undermined Joan’s confidence in the general idea that there is some link between breastfeeding and the development of allergies. The fact was that Joan had breastfed for as long as possible and made dietary choices while doing so that were not informed by changing medical recommendations. Now that evidence backed a new finding, the results were not relevant to her. It was of no use to her to obsess over the role breastfeeding might play in developing allergies. Instead, as she explained in our interview, she cast her lot wholeheartedly with another idea, the hygiene hypothesis.

Links between breastfeeding and food allergies are not the only source of mother guilt; ongoing debate about food introduction and feeding similarly triggers these feelings. In her book, which was introduced in the previous section, Robyn O’Brien (2009, 76) describes the “mama guilt” she felt upon later reflection on her choices to consume soy during her pregnancy and feeding her children soy-based formula. The research she conducted for her book has since convinced her that soy, particularly genetically modified (or GMO) soy, is a main culprit behind the rise of food allergies. Soy is present in obvious foods, like tofu and soy-based drinks, as well as in food thickeners and texturizers and, most troublingly for O’Brien, in so-called “hypoallergenic” infant formulas. O’Brien’s guilt is connected both to the feeling that she did something wrong and that she allowed herself to be taken in by the promise that expert scientific knowledge had the best advice about how best to produce healthy children. The alternative would have been to raise her children following her own “maternal instincts”. As she writes, “[t]he idea of 25 percent of all formula-fed babies being part of some giant science experiment made me shudder – particularly when you consider that it’s a science experiment that neither they nor their parents ever knowingly signed up for” (O’Brien 2009, 78). Her unwitting participation in this experiment, she asserts, is the cause of her son’s deadly allergies.

The hygiene hypothesis is another source of guilt for O’Brien, and for many other mothers and adults with food allergies. The hygiene hypothesis, first proposed by David Strachan in 1989, connected rates of hay fever in English children and young adults to the number of siblings in a family through a retrospective analysis of over 17,000 individuals. Strachan interpreted the results to suggest that “allergic diseases [could be explained] by infection in early childhood, transmitted by unhygienic contact with older siblings, or acquired prenatally from a mother infected by contact with her older children [and by l]ater infection or reinfection by younger siblings” (Strachan 1989, 1260). The hygiene hypothesis continues to offer a possible explanation for allergic etiology, though the proposed mechanisms have proliferated since 1989 (Strachan 2000). O’Brien bristles at the way such theories can instill a sense of guilt in mothers of allergic children: “they’re saying that we moms are the problem. If we’d only lighten up on the hand-washing, they suggest, the allergy epidemic would vanish right into that new layer of dust covering our formerly spotless floors” (O’Brien 2009, 42). This keenly felt “mama guilt” is a typical expression of the self-blame that is a staple of food allergy mothers’ conversations online and in person.

Although O’Brien’s criticism of mainstream scientific thinking about food allergies is often viewed with skepticism in the food allergy world, the resulting anxieties she mentions are common. For her, as for Jenna and Joan, the whiplash between initially understanding that certain foods (including low fat, plant-derived, and whole foods) are “healthy” for mainstream eaters and then coming to terms with the surprising fact that they trigger serious allergies in members of one’s own household undermines her trust in expert advice. Blaming the modern food production system thus deflects blame from herself as much as it offers a plausible answer to the etiology question.

Scientific research on links between food exposure and food allergy makes up another active area of research on food allergy etiology. Rather than investigating GMOs, as O’Brien advocates, scientists have been largely focused on the links between exposure to common food allergens and the incidence of allergies (Lack 2012). The most highly acclaimed study on this topic to date, the Learning Early About Peanut Allergy (LEAP) study, was published on February 26, 2015 in the *New England Journal of Medicine* (*NEJM*), one of the top medical journals in the world. The study, led by English physician-researchers George Du Toit and Gideon Lack, followed 600 children with severe eczema, egg allergy, or both from between 4 and 11 months of age until 60 months of age. The subjects in the study were randomized to either eat or avoid peanut, provided in the form of a peanut-dusted Israeli children’s snack called Bamba (Du Toit et al. 2015). Children who consumed peanut regularly were found to have a lower incidence of peanut allergy. The researchers attributed the effect of treatment to the ability of early oral exposure – that is, eating potential allergens – to promote “tolerance” to food proteins rather than allergy. Despite the clinical demonstration of efficacy, the article conceded that “oral tolerance is an incompletely understood immunologic phenomenon” (Du Toit et al. 2015, 804). Finally, the food allergy community sighed, evidence from a large, randomized controlled trial (the gold standard for generating biomedical knowledge) suggested a detectable correlation between infant feeding decisions and allergic outcomes. The study was hailed as a potential turning point in knowledge about food allergy, with a worldwide consensus statement encouraging the medical community "to rapidly implement these findings and change the culture of early feeding practices" (Fleischer et al. 2015, 603).

A number of popular articles analyzing and responding to these results have appeared in the months since the study was published. Headlines like "Feeding Infants Peanut Products Could Prevent Allergies, Study Suggests" appeared the day of the announcement, stoking public interest. Some of the interpretations triggered concern among food allergy parents, researchers, and food allergy advocates who worried about parents taking peanut introduction into their own hands. Leading researchers in the field from the highly esteemed Mount Sinai Jaffe Food Allergy Institute, for example, declared that implementation of early peanut introduction in high risk infants was not "ready for prime time," unless done under the guidance of a physician and preceded by allergy testing (Gruchalla and Sampson 2015).

Writer Henry Ehrlich, a rare man in the largely female food allergy community who commonly speaks at food allergy events, used his website as a platform to urge caution in interpreting the results with his own writing and by featuring the words of others (Ehrlich 2015; Stukus 2015). He linked to the appeal of his blogging protégé, food allergy mom and biologist Jessica Martin, who wrote,

> Refrain from reading any and all article commentary from non-experts to avoid the 'I told you so' and 'stupid, fearful parents for not feeding your kid our nation's best, right-to-eat it anywhere, delicious, nutritious snack.' These comments are examples of ignorant people wrongfully interpreting scientific findings through a way too generalized media filter to support what they already 'believe' to be true. … This study was aimed at preventing peanut allergy in infants at high risk of developing food allergies. If you are already dealing with a food allergy, this study does not apply to your situation. (Martin 2015)

Yet the initial excitement persisted for months in the popular, non-food allergy press. A December 2015 ode to the merits of impulsively buying and feeding one's child crates of Bamba, for example, ruffled many feathers in the food allergy community (Hanel 2015).

In addition to sympathetic concern for parents who may trigger allergic reactions by feeding their young children peanut, food allergy parents and advocates worry about the actions of unscrupulous family and community members. In particular, they worry that this research will fuel the attitude among some that food allergy parents and patients are “fakers” who inflate the seriousness of the disease simply to garner attention. The comments sections on feature articles about the research, which often include comments ridiculing cautious parents of food allergic children, suggest that their fears may be reasonable (Pollack 2015). Pointed comments nostalgic for a childhood steeped in peanut butter and jelly sandwiches implicitly critique finicky modern mothers – faulty women who produce weak, damaged children. One commenter’s response makes this position clear: “It's about time. As others have said, I survived my childhood on PB&J - brought it to school nearly every day as did most of my classmates. Not one incident ever ... yet schools now ban PB? Ridiculous.”

The “mother-blame” felt by parents of food allergic children arises in part in response to the confusion concerning allergy etiology and the changing biomedical guidelines concerning prevention. Not only do these guidelines confuse mothers themselves; parents fear they also muddy the waters of public understanding of food allergies, potentially justifying lax attention to hygiene and dietary restrictions around allergic children. In response to the rising anxiety and self-blame among food allergy mothers, some allied with the community are pushing back to applaud “good enough” parenting. Take Heather Hewett’s feature in the 2014 issue of *Allergic Living* magazine. Hewett, a women’s studies scholar and professor, writes about the “litany of self-recrimination” she experiences following a mix up of glasses of soy and cow’s milk that lands her daughter in the hospital with anaphylaxis (the second such story I came across in my research) (Hewett 2014, 89). Hewett writes that she feared she was “a Bad Mother” because she “[ate] too many peanut butter cookies during pregnancy… wait[ed] too long to introduce particular foods… [or didn’t] expos[e my daughter] to enough germs and dirt” (89-90). Being a “Good Mother” of a child with a disability in modern America means, in her reading, being a “fearless Warrior Mom” who never makes mistakes and always protects her child from all sources of harm. But food allergy mothers are ready for a break, she concludes, and deserve to be content with “good enough mothering,” accepting mistakes and adapting to situations as they arise.

Yet despite such positive messages, the feeling of letting down one’s children is a very real part of raising food allergic children. Food allergy moms worry that they either directly caused their child’s food allergies through inappropriate dietary interventions or by proxy, by failing to detect and override bad advice from experts. When risk factors materialize in one’s life in the form of an observed, diagnosed disorder, statistical probabilities describing the multiple factors that could have contributed in ways often impossible for one mother to predict seem distant. Instead, mother takes the blame.

### Risk and Embodiment

The patient and parent narratives in this chapter, deeply in conversation with biomedical research on food allergy etiology, describe encountering, interpreting, and refashioning key epistemological assumptions about allergy risk factors proffered by medical experts. Patient experience and intuition may be confirmed by one medical practitioner or scientific theory but contested by another. Biomedical models of food allergy risk factors provide traction for forensic projects, including investigations of the harms of modern life and self-blame among food allergy mothers. In food allergy worlds, risk is a personal metric emerging from interpretations of illness narratives and generating fear, anxiety, and mother-blame.

A close examination of how people living with food allergies interpret their disease states suggests that simply critiquing risk discourse as a means of exerting biopolitical control over populations in a Foucauldian vein (Foucault 1977, 1997) does not account for the exigencies of risk management in everyday life with a chronic disease. In our current historical moment, when blood tests reveal one's cost to society, one's fitness for parenthood, and one's likely cause of death – in short, one's fate – risk now functions in society as a personal metric as well. Within food allergy worlds, the numbers to live by – the results of medical tests and statistical predictions of disease risk – must be verified by running them through the program of personal historical narratives.

Thinking risk at the individual and interactional level in this way departs from the expert epistemology of risk that has been critiqued by social scientists: a technology designed to measure trends in populations that operates as a justification for social control of individuals' behaviors and morality (Foucault 1977, Conrad 1992, 2005). Breastfeeding all babies, for example, is understood to promise to reduce the rate of food allergies in the American population by biomedical experts. Guidelines therefore recommend exclusively breastfeeding "high-risk" infants (that is, infants with close relatives with allergic conditions or who develop eczema early in life) for at least 4 months if their parents hope to ensure their children's good health later in life. But if two children are breastfed and only one develops allergies, the mother of the food allergic child might come to suspect that the pressure to breastfeed is overblown. She may integrate expert knowledge as one element of several that help to explain food allergy etiology, or choose another expert theory as her go-to explanation. Making sense of recommendations based on a technocratic risk calculus entails fact-checking them against the facts of one's own life.

Theories of embodiment, particularly those articulated by anthropologists, provide traction for thinking across the shifts in scale and epistemology that it takes to get from population statistics to embodied experience. Thomas Csordas (1990) famously urged anthropologists to take bodily experience seriously as an object of study, asserting that the body is “the existential ground of culture” (5). Understanding how individuals make meaning out of bodily experience, in this reading, provides one sort of data on the cultural significance of different modes of comprehending the world. Kathryn Lynn Geurts’ (2002) work on Anlo-Ewe embodiment in Western Africa and Rachel Prentice’s (2012) work on the practical and ethical formation of surgeons-in-training elaborate upon Csordas’ observation. In Geurts’ analysis, for example, bodily experience is an anchor for Anlo-Ewe moral codes and moral reasoning, contributing to their unity as a community. When it comes to life with food allergies in the United States, shared experiences concerning bodily vulnerability – both experienced as an individual subject and witnessed as caretaker of allergic children – similarly contribute to shared moral reasoning concerning risk. Such reasoning guides decisions about life and death in real time, interprets past failures, and theorizes about future possibilities and potential catastrophes.

Individual embodied experience is closely linked to memory and to the particular capacities of each individual’s body. Though the experiences are varied, there are similar words, events, and narrative arcs that emerge when listening to many food allergy illness narratives side-by-side (Kleinman 1988). Adults with allergies share these stories amongst themselves as a way to build community and feel less alone in their bodily suffering; mothers who share them find they are not alone in their mother-blame and, as chapter 6 will show, they find support and even political awakening in their telling. These stories are both affective and effective.

In this light, risk is deeply intersubjective. Reading, writing, debating, and discussing the bodily and life-historical experiences that are characteristic of life in food allergy worlds offers those living with the condition a way to feel connected, and perhaps safer, in a precarious body. As with Rapp and Ginsburg's "disability worlds," individual "allergy worlds" are the building blocks of a new "kinship imaginary" in which similarities in how individuals relate to the social and material world through their dysfunctional bodies is a justification for forging deep social ties. In private conversations, support group meetings, and online networks, the shared experience of living with allergic bodies and managing their risk of harm brings parents and sufferers together. This analytic offers more generative possibilities than Rabinow's (1992) notion of "biosociality." In a biosocial world, individuals come together on the basis of shared biological indicators of disease and shared diagnoses. As I will discuss in chapter 6, this mode of social relations provides opportunities for political and social actions that ease life with a serious illness at the same time as they make patient groups vulnerable to manipulation. Yet in the original conceptualization of biosociality, embodied experience takes a back seat to the power of bio-technological tools to modulate the present and predict the future. "Disability worlds," by contrast, leaves open the possibility – realized in many corners of the food allergy community – that individuals seek and find each other in spaces parallel or alternative to the mainstream platforms of biomedical science.

Living at risk of allergic reactions is a highly specific, embodied way of being, but one that can also be constitutive of social bonds, affects, and creative reformulations of widely accepted biomedical explanations of the ills that befall human bodies. This is not to say that present-day risk logic is necessarily beneficial, or that it is not *also* a mode of social control. This chapter sought to take seriously what it is like to *live with* the feeling that one's body (or the body of another that one is responsible for) is constantly on the verge of harm or death. Interrogating the scientific theories of the allergy etiology is a modern, technoscientific way to come to terms with the temporariness of human existence *in the face of* and *using the tools of* biomedical orthodoxy, which tells use that with proper maintenance techniques, we can all have it all, forever. In an era when “more life” is a positive moral value promulgated by pharmaceutical companies and when the promise is that all ill health will soon be prevented due to our finely-tuned understanding of what constitutes a risk to health (Dumit 2012), how else should individuals make sense of their own suffering?

# CHAPTER 5

# THE HYGIENIC SUBLIME: MAKING FOOD SAFE FOR PEOPLE WITH FOOD ALLERGIES

In the United States, the eight most common allergens – the “top eight” in food allergy community parlance and “major allergens” in legal discourse – are wheat, milk, eggs, fish, shellfish, soy, peanuts (a legume), and tree nuts. According to FARE, a leading food allergy advocacy organization, these eight foods are responsible for over 90% of allergies to foods in the US (FARE 2015). There is no medical treatment that can prevent a person from having a reaction after exposure to these foods (or any other allergen) if they have an allergy to them. Nor is there a reliable, widely used method of preventing allergies from developing in the first place. The only “treatment” for food allergies is to strictly avoid the food to prevent reactions. But avoidance is harder than it sounds: cross-contact in the manufacturing or cooking process, residues of allergens in the environment transmitted by hands, surfaces, or dropped crumbs can introduce enough of an allergen to trigger anaphylaxis in some individuals. Following a diet and a lifestyle that strictly eliminates allergens is the best form of medical care for people with food allergies. These practices are constitutive of a “hygienic sublime” in which demonstrations and enactments of “safe food” emerge from the practical and immediate need for foods free of allergens, the desire to demonstrate that the community cares for people with food allergies, and the modern capitalist dictum to make money while doing good. In the hygienic sublime, the risk of a reaction is negligible while food remains tasty, easy to access, and enjoyed with friends and family.

Food preparation and exchange is fundamentally about providing care for oneself and for other people. The importance of food as care for food allergic people is clearest when others *fail* to take care – when they offer or feed allergic people with foods that could trigger their allergies. Many food allergic people take the common occurrence of being offered food containing their allergens as evidence that others “don’t care” about their wellbeing and their condition. Failing to take care in this context could mean trying to maliciously trick the food allergic person into eating their allergen to test whether they really have allergies, but it could also be as subtle as neglecting to carefully read and interpret the ingredients on a food label. A perceived lack of care cuts particularly deeply when the offender is a family member, close friend, or trusted colleague – that is, when the nature of the relationship presumes some preexisting degree of moral obligation, even though it may primarily concern other social spheres or practices.

Like many care practices in American culture (Abel and Nelson 1990), the food preparation techniques used to manage food allergies in the home are often deeply gendered. Food preparation is traditionally conceived in the United States as a domestic practice to be carried out in the home by a maternal figure charged with keeping her family healthy and safe. To cook nutritious, pathogen-free, aesthetically pleasing food has been a central pillar of the domestic expectations for women in this country for more than a century. Food preparation has been subject to rationalization and regimentation along with other domestic practices over the course of the 20th century (Cowan 1976; Kline 1997; Bijker and Bijsterveld 2000), yet it still signifies hominess and maternal care (Parr 2002). When food is literally the best medicine, and the wrong food can cause serious illness or death, food preparation takes on even deeper moral connotations.

In addition to being nutritious, pathogen-free, and aesthetically-pleasing, for food allergic people food must also be purely what it is held out to be, absolutely free from known or unknown contamination that may contain an individual’s allergens. Within food allergy communities, this question of purity is often articulated as one of “safety.” Foods that are free from an individual’s particular set of allergens are “safe.” “Unsafe” foods are those that are known to contain allergens, as well as those whose provenance – or the provenance of any of the ingredients of which they are constituted – is unknown. The “traceability” (Lezaun 2006) of these foods is at stake, much like the traceability of GMOs in Europe. Unlike that case, however, much of the infrastructure is ad hoc, designed by consumers and a small number of trend-setting specialty food manufacturers. If an ingredient cannot be traced back to the plant, animal, or laboratory from which it ultimately originated, then there is room to doubt its purity. In the absence of detailed information about ingredients, it is assumed possible – probable, even – that a food was made with equipment also used with allergens. If it was handled using the same tools or on the same surfaces as food with an individual’s allergens, it could contain particles of those allergens. The traceability of a food is understood by the food allergy community to correlate to its riskiness; tracing foods back to the source is a forensic technique (Douglas 1990) for containing the risk posed by food to allergic bodies. The financial cost of these systems has so far been borne directly by food allergic consumers and their families in the form of higher prices for traceable foods.

The question of purity is not a new one to anthropologists. Mary Douglas famously noted the opposition between purity with pollution in accounts of religious practices in anthropology and historical studies of religion. Those things seen as “polluted” were simply, Douglas (1966) argued, “matter out of place” of the doctrinally correct ordering of the universe. Encountering those things at all, or in a way or time that contravenes the social ordering of people and things, transfers pollution from those things to the person who upsets this order. Drawing an exact parallel between religious pollution and the concerns about purity harbored by those living with food allergies is imperfect, however, because “purity” as a property of foods has both semiotic *and* material importance. Failing to maintain a high enough level of purity of foods for allergic individuals unequivocally has immediate, observable consequences. Impure foods can trigger allergic responses, including the severe, multi-system reaction known as anaphylaxis. Yet many follow strict elimination diets that exclude polluting substances at much lower concentrations than can be experimentally verified to trigger allergic reactions. Seeking and maintaining an absolute level of purity imparts a feeling of control; it *signifies* freedom from pollution, and thereby safety, to food allergic people.

The heightened standards of purity sought by people living with food allergies is characteristic of a heightened hygienic sensibility, which I call “the hygienic sublime.” Like David Nye’s “American technological sublime” (Nye 1994), the hygienic sublime is a moral and aesthetic experience. Rather than connoting progress and national unity, the subjects of the technological sublime, the hygienic sublime signifies safety and care. The ideal of *absolute* purity as well as the real-world practices undertaken to achieve it matter greatly to people managing food allergies. They are also quite aware of the near impossibility of consistently achieving this ideal, and the difficulty of verifying when it is accomplished and when it is not prior to encountering an allergen, facts that trigger stress and worry. Part of what is “sublime” about the hygienic sublime is its very status as an unattainable, yet deeply desired, state of affairs. The clean, volatile organic compound (VOC)-free and nut-free kitchen, the meticulously researched ingredient supply chain, the homegrown vegetables free of comingled grain or vegetable contaminants: these are the best expressions of the sublime aesthetic. So powerful is its allure that the US Congress, specialty food manufacturers, and corporate consultants have joined parents and allergic adults in enacting this ideal. Attaining, or at least convincingly performing, the hygienic sublime has the power to instill feelings of belonging and safety, as well as to direct corporate policies and drive sales, while reducing the risk of allergic reactions toward zero.

The moral question concerning food purity for people living with food allergies boils down to this: Who can I trust with my life or the life of my child? This chapter will examine a variety of strategies used both within and outside the home, which are used to make (at a material level), enact (at the level of personal practices and corporate policies), and perform (at a rhetorical level) trustworthy "safe foods." The next section starts by discussing some strategies people living with allergies use to ensure that their domestic environments stay appropriately safe and pure. Later sections will discuss two case studies where small companies have adopted a caring stance toward food allergic customers. The hygienic sublime structures the caring practices and safety aspirations of food allergic living, organizing the pursuit of purity and profits alike.

## The Food Labeling Problem

Concern about how to maintain purity (and thereby ensure safety) of the foods eaten by people with food allergies motivates the pursuit of the hygienic sublime. Purity and safety are difficult to attain, given US food production techniques and ingredient labeling requirements for packaged foods. The legal and regulatory frameworks designed to enforce standardized, comprehensive ingredient disclosures often do not do so in a way that allows for people with food allergies to easily access the information they need to feel safe. Regulations concerning food packaging and labeling mandated by the Food Labeling and Education Act of 1990, including rules requiring fuller ingredient labeling, were phased in over the course of the 1990s to improve  upon weaker frameworks instituted in the 1970s (Porter and Earl 1990). Even with new rules, ingredients could be (and in many case still can be) lumped together as "spices" or "natural flavorings," creating difficulties for people with food allergies who must avoid even trace amounts of their allergens. "Major allergens" were not yet legally defined, and manufacturers did not have to disclose their presence. Chemical names like "casein" or "albumin" could be listed on the label without any indication that these proteins are derived from milk and eggs, respectively. To read a label, one therefore had to become an expert at translating the scientific jargon of food processing chemistry into the lay language of food. Moreover, potential cross-contamination of manufacturing equipment and spaces was not required to be labeled. To get such information, consumers had to grill manufacturers directly, but they were under no real obligation to be forthcoming with information. Expertise in label-reading and information about supplier and manufacturing changes were potentially life and death matters through the 1990s.

The situation improved somewhat in 2004 following the passage of the Food Allergen Labeling Consumer Protection Act (FALCPA) (Food and Drug Administration 2004). This law amended the Federal Food, Drug and Cosmetic Act of 1938, the act that established the regulatory authority and purview of the US Food and Drug Administration (FDA). FALCPA mandates that ingredients consisting of, including, or derived from the top eight "major allergens" (peanuts, tree nuts, milk, egg, wheat, soy, fish, and shellfish) which were intentionally or incidentally added to a food must be declared using their "common or usual name." That is, foods that contain those allergens or may have come in contact with them during processing must now be declared on the label in plain language. They can be declared within the ingredient list or added parenthetically when the use of a technical term makes the common name of the food not immediately obvious. Or, an added "Contains" statement can be placed near the ingredient list that declares any major allergens present in the food. Today, foods that contain the ingredients casein or albumin in the ingredient list will say “contains milk” or “contains egg.”

But there are several loopholes that undermine the practical effectiveness of FALCPA. First of all, the law only applies to foods regulated by the FDA. Since meat and some egg products are regulated by the United States Department of Agriculture (USDA), there is no labeling requirement for these ingredients. This can cause headaches at Thanksgiving, for example: commercially packaged turkeys often contain milk derivatives used as meat tenderizers. The same holds for alcoholic beverages, which are regulated by the Alcohol and Tobacco Tax and Trade Bureau. Many spirits are brewed with tree nuts (a top eight allergen) and some beers are processed with crustacean shells (another top eight allergen) to improve color and clarity. Another major limitation is that allergen declarations are voluntary, not mandatory. The manufacturer decides whether to include disclosures of top eight allergens on their food package label. If a disclosure is present, it must be accurate and comprehensive, listing all allergens or allergen-derived ingredients in clear language within the ingredient list or following the ingredient list. But if there are no disclosures, an item could have come into contact with any other food under the sun. Some labels include “may contain” statements, which are voluntary and unregulated. They indicate that a major allergen may be present but are not consistently used and considered unreliable among expert patients and advocates in the food allergy community.

The most annoying bugaboo for food allergic individuals and parents – a subject of endless chatter, suspicion, and complaining – are the law’s exemptions for items like “natural flavoring,” “spices,” and highly refined oils. For example, nuts may be a component of or come in contact with “spices.” Citric acid is added to many foods as a preservative and flavor enhancer. It is an unlikely allergen from the point of view of biomedical professionals because it is not a protein, but several of my informants claim to be allergic to it. The flavoring loophole allows companies to protect trade secrets but severely undermines the trustworthiness of the labeling regime for those who rely on it to avoid allergens. In the case of highly refined oils, the scientific evidence suggests that they are highly unlikely to trigger food allergies. An extensively refined oil should be free from proteins if properly manufactured, and therefore it should not be allergenic. However, there is anxiety in the food allergy community about the reliability of such manufacturing processes, as well as anxiety that particular individuals may be so sensitive to allergens that they react to undetectable levels of proteins in the product. Overall, the law is seen as a first, but deeply flawed, step in the food allergy world.

Even with disclosures, it can be difficult to know when it is necessary to take the time to read a label. Allergens lurk in unexpected foods, such as flavorings, dough conditioners, texturizers, and added sources of protein. Food allergy advocates like Jenna and Robyn O’Brien might also find genetically modified foods suspect, as discussed in the previous chapter. Sliced, shelf-stable bread, for example, now more often than not contains much more than flour, yeast, salt, and water: soy and milk ingredients maintain its soft texture and nuts add protein. Snacks that do not appear to contain peanuts or tree nuts are often produced on the same equipment as foods containing those ingredients. Allergens – particularly particles of oily foods like nuts and fish – can also lurk in the hinges and gaps of assembly line machinery long after the production run changes. Food flakes and oil residues can remain in crevices, even after sterilization renders the production line legally “clean,” contaminating foods that are otherwise nut-free.

Simply avoiding processed foods from the diet altogether would remove much of the risk of cross-contamination on production lines. However, this is unthinkable for most of my middle-class interlocutors both because of the time pressures of middle-class life and the aspirations and nostalgia indexed by processed foods in the United States. Preparing whole foods from scratch is a time-consuming practice; while it can save money, it costs time. Time is unavailable to most families and individuals in this era when few adults can forego wages for personal responsibilities, including illness and quality of life. Parents not only work but also put in second shifts ferrying children to after school activities in hopes of preparing them for admission to good colleges and entry to the Good Life. Equally importantly, the kinds of food one eats symbolizes one’s place in society. Providing the traditional favorites of American childhoods, such as peanut butter sandwiches, chocolate chip cookies, an ice cream cone in July, and sugar-laden birthday cakes for toddlers, is of the utmost importance to my interlocutors. These foods signify childhood, remind them of their own happy memories, and allow them to feel that their children – and by extension they themselves – are integrated into the wholesome flow of middle class American society.

Instead, food allergic adults, families, and their allies have come up with a variety of strategies for safeguarding the food supply for food allergic people. These strategies incorporate hygienic practices in the home, financial maneuvers in the restaurant industry, and supply chain management in food manufacturing. All of these strategies are geared toward ensuring and increasing the traceability (Lezaun 2006) of allergens. The legal apparatus for allergen traceability is filled with holes: most guidelines are voluntary, and they govern the contents of the final product, not the production lines that produce them. Intentions are complicated by the material properties of commonly allergenic foods, like peanut, which circulate in the environment according to their own agency, foiling human intentions to control them (Murphy 2006; Mitman 2007; Nash 2007; Langston 2008, 2010), as well as the admixtures produced by modern supply chains that move foods from one place to another (Lezaun 2006). The limitations provide fertile ground for the enactment of the allergic hygienic sublime by people taking care of food allergic bodies. The roots of this sensibility lie in the home and the ad hoc practices of food allergy parents and patients.

## Preserving Purity in the Home

It was dusk on a Sunday evening in September 2014, and I was sitting on an airport shuttle bus on the outskirts of a southwestern city with a half-dozen participants from a weekend conference for food allergy bloggers. We were on our way to the airport where each of us would board a different red-eye flight home, arriving in time for responsibilities to resume on Monday morning. Ever the ethnographer, I struck up a conversation with a cheerful woman seated behind me. She ran a specialty foods business with her husband that they founded after discovering how few snack options there were on the market for their two dairy and nut allergic children. She had recently quit her day job to devote herself fully to the business, for which she found herself working as many hours as a full time job. As we spoke, she revealed an important part of her philosophy of parenting food allergic kids: the home should be a space where they feel completely safe and at ease. For her, this meant keeping all items that anyone in the household was allergic to out of the home. The foods produced by their business were designed to be safe for everyone in their family.

A woman across the aisle from me – as it turned out, a homemaker with six children – joined our conversation. Her philosophy was the opposite: kids will have to learn to avoid their allergens eventually, so why not start at home? She allowed most foods into her home and taught each child to avoid what they were allergic to at a young age. This also served a practical purpose, since excluding all of the household's allergens would have made it impossible to provide balanced nutrition to all six children, even with the time that she had as a full-time mother to strategize meal planning.

This conversation came at the end of a long, emotionally charged weekend where writers (mostly women), parents (also mostly women), representatives of allergy-friendly products and non-profits (yet again mostly women, although with a smaller margin), and researchers (mostly men) had assembled to learn about the science of food allergies, share their experiences and work, and refine their writing and business strategies. It brought into relief the competing demands that shape decisions about how to make a home “safe” for people with food allergies. Exclusion of allergens, it turns out, is complicated and contingent. The fact that the homemaker had so many children with so many conflicting allergies made it more challenging for her to prepare meals safe for everyone than the mother in a two-working-parent household who only recently quit one of her two jobs. Her decision to allow allergens in the home, as she articulated it, was only partly practical. It was also moral: it was her responsibility to prepare her children for the world beyond the home, and learning how to manage their allergens was an integral part of that preparation. The working mother, by contrast, sought a much greater degree of control over which substances entered her house; she even started a company to ensure that treats free of her children’s allergens could be obtained without having to make them from scratch.

The technical skills required to ensure safety, which include learning how to read food labels and relearning the practical chemistry of food preparation, become embedded in how people living with food allergies encounter food. These skills are deeply imbued with moral implications, since even a minor accident or oversight can cause significant harm to an individual with food allergies. STS scholars have often thought about patients as “lay experts” who participate in the construction of expert scientific knowledge about their condition following battles for credibility and legitimacy with “true” scientific expert communities (Epstein 1995, 1996; Rabeharisoa and Callon, 2002; Landzelius 2006). Their  self-care and self-monitoring “skills” become legible as legitimate knowledge when they can perform a certain level of professional expertise. With food allergies, some kinds of patient knowledge become objects of expert concern while others do not. For example, lay hygienic expertise concerning how to clean eating surfaces to remove allergens has been tested experimentally and reported in the scientific literature (Perry, Conover-Walker, et al., 2004). The preparation of safe food figures differently: while patient representatives have played roles in crafting regulatory requirements for food labeling, how to prepare “safe food” is constructed as outside the area of concern for most biomedical experts (save a few dieticians and therapists with personal experience with food allergies). These mixed outcomes reflect a triaging (Nguyen 2004) of patient advocacy priorities based on the food allergy’s community understanding of the extent to which regulatory and biomedical experts are willing to intervene on the challenges they face.

After returning home from the blogger’s conference, I stayed in touch with many of the participants whom I had met over shared meals and between speaker sessions. I had instantly bonded with one woman in particular, who I will call Alice. Alice was a middle-aged woman from the west coast. During the opening ceremony of the conference, she received an award honoring her 20 years of leadership in the community as a food allergy cookbook writer, mother, and support group leader. Throughout the conference, she stood out for her poise and professional appearance, wearing fitted black and gray dresses that ended above the knee, topped with a stylish, dark brown bob and a wry half-smile. Her kids were grown by the time we met, but when her oldest son was diagnosed with food allergies in 1991, the condition did not have the same level of visibility that it has today. Her son was often the first child with food allergies whom doctors, teachers, coaches, and other parents had encountered. As a stay-at-home mom, she was in charge of ensuring his safety at home, at school, and at play.

One of the biggest challenges Alice faced early on was the way that foods were labeled in the 1990s. Each of the top eight foods – of which Alice's son was allergic to peanuts, tree nuts, dairy, and eggs as a child – are simple ingredients found in a wide variety of foods. Without labels to declare minor ingredients and the possibility of contamination when her son was young in the 1990s, it was impossible to know with certainty whether a small amount of any of the allergens that might affect him was in manufactured foods. To manage this uncertainty, she cleaned out her cabinets of any packaged foods that might contain his allergens and committed herself to cooking all of his meals from scratch at home. This turn of events set the stage for her future publication of the first cookbook targeted at food allergy families.

The issue of cross-contamination came up repeatedly in my later phone interview with Alice. In the 1990s, she and other allergy moms were pretty much on their own in figuring out what it was and how to avoid it, as she explained:

> There were a lot of things that today are sort of common knowledge in the food allergy world that we were just figuring out. Such as the idea, the concept of cross contamination… We couldn't figure out why the kid kept reacting to things. I'd think, but that doesn't have milk in it! It didn't occur to me that he could react to what was on the knife, or what was on the equipment in the manufacturing plant. It didn't occur to me because there were no resources and there was no common knowledge.

Despite her vigilance, near-misses and mishaps sometimes occurred, especially when other mothers tried to help her take care of her son. Prior to one birthday party, for example, a mother had used one of Alice's own recipes to bake cookies that would be safe for Alice's son. When the mother prepared to serve them, Alice decided to double-check the safety by asking about the ingredients and brands used. Finally, the mother declared that she buttered the cookie sheet with dairy-based butter. Without thinking, she had contaminated the cookies with dairy and made them unsafe for Alice’s son. On another day, Alice had left her son, still a toddler, with a friend who she had trained to recognize and treat the symptoms of allergic reactions. After some time, her friend called, explaining that Alice’s son was breaking out in hives on his face. Alice rushed to her friend’s home and discovered that she had wiped his face with the same washcloth that she had used for her own son; in effect “she had wiped allergens all over his face.” The hives spread onto his legs, suggesting that the highchair he was seated in was also coated in allergenic food residue. Alice summed up these stories by lamenting that “even if you find another mom who’s willing to take him on and you send the food and you’ve gone through the emergency procedures, little details like that wouldn’t occur to the average person.”

Alice’s recollections indicate the level of detail that people living with food allergies need to attend to in order to effectively avoid their allergens. In Alice’s words, “managing food allergies is nothing but detail. … Watching somebody else’s kid who has it is a huge responsibility.” Getting the details right can be the difference between health and sickness, or even death. As Alice’s stories illustrate, many people living with food allergies need to be vigilant about their surroundings at all times as well as about what goes on at mealtime, since it is possible to react to contact as well as ingestion. In addition to reacting to skin contact, allergens could be ingested when a child puts their fingers in their mouth, triggering a full-blown anaphylactic reaction. Constant watchfulness is difficult enough for food allergic individuals and their immediate family, and even more so for extended family and helpful friends. Caring for a food allergic child carries with it a heightened duty to protect them from hazards in the environment. While an outside observer may conclude that there are practical limits to the amount of detail an individual can monitor and control, the intersection of logics of risk, safety, and care creates a situation where allergy moms (and other caretakers) feel that no effort is too great, and no level of hygiene is too high or unattainable, at least for a period following diagnosis. Controlling the risk of reactions through an intensification of care practices to ensure safety is the order of the day for food allergy parents. The hygienic sublime exceeds ordinary reason and, perhaps, practical usefulness. The ideal of perfect safety motivates extreme practices.

The state of current effective intervention for food allergies – strict avoidance of allergenic foods – also strengthens the moral connotations of domestic work and intensifies the duty of mothers to become domestic experts. Indeed, most of the parents I encountered who were in charge of meal planning and preparation in food allergy families were women. It is telling too that one of the few male food allergy bloggers prominent in the community writes about eating during his travel adventures, rather than eating at home. I know of no women food allergy bloggers who blog exclusively about meals eaten outside the home. The dozens of women bloggers I've read write about life close to home: baking birthday cakes, shepherding children on field trips, and smoothing the ruffled feathers of other moms, extended family, and school officials. To provide care for food allergic children, many parents – more often than not mothers – choose to stay home with their children rather than to work, an increasingly unusual choice in working- and middle-class American society. In doing so, they inhabit the female-gendered role of homemaker, forfeiting the financial stability and social status that go along with professional achievement outside of the home. It is a choice that often needs to be made out of necessity, since cooking food for food allergic people is a complex and risky process, and one upon which their lives depend.

Returning to my conversations with Michael, a food allergic adult whose experience was featured in the previous chapter, offers another view of how the hygienic sublime is enacted in the home. Michael and I discussed the ins and outs of food preparation in a conversation we had over the phone late in 2014. He has been diagnosed with allergies three years previously and had an infant daughter who was also developing food allergies. He was, notably, the only stay-at-home father of food allergic children that I interviewed in the course of my research, a role he only took on because his own food allergies and environmental sensitivities rendered him unable to work. While becoming a stay-at-home dad had its rewards, he was still devastated by his inability to have an active social and professional life. One wonders whether a mother would feel the same sense of mourning that he expressed during our interview and in subsequent conversations. For Michael, unlike many of the mothers I've spoken to in my research, being the stay-at-home parent was not a choice or even a possibility prior to his allergy diagnosis.

When I interviewed Michael, he described the process he went through to make his kitchen equipment safe, after figuring out that his chronic illness stemmed from food allergies. It was a two-year process because, as he put it, "you can't just go into a regular kitchen and yank all the allergens because people don't know what's in their food. It's very difficult to extract allergens out of a kitchen. And of course, out of the pans." The nature of the modern food system, household logistics, and the materials of kitchen equipment itself (specifically, as Michael went on to explain, pans treated with non-stick coatings) all conspired to make eliminating allergens from the home a lengthy and complicated procedure. As we talked, he toured his kitchen and he told me what he saw. Boxes of onions, potatoes, and butternut squash from local farmers and his own garden sat on the floor, banishing any hope of a "clean kitchen." There were "a few crockpots here and there," and an extra freezer where he stored servings of bulk meals for days when he felt too ill to cook. One of his allergens included corn, which, he reported, can leach out of food-grade plastics. He rid his kitchen of all plastics, with the exception of a single silicone spatula. Modern conveniences like prepared foods and high-tech materials were gone, replaced by stainless steel and boxes of basic, raw vegetables. It was, in his words, “no frills.”

There were more problems to solve than remaking his kitchen. Michael also had to find new ways to obtain food. While some of his measures were extreme due to his body’s extreme sensitivity, the overall sensibility he expressed – seeking fresh, raw, unprocessed foods that he could combine in ways that maximized nutrition and excluded his particular allergens – was one that is shared by some people living with food allergies, particularly adults managing their own allergies. His wife had ceded control over buying and preparing food early on in his illness, after accidentally triggering allergic reactions when she prepared meals. When we spoke, Michael couldn’t even enter “regular grocery stores” because he “react[s] to the bakery and all the other garbage in there.” Instead, he made regular trips to a health food store (which was, sadly, closing), a food co-op, and a farmer’s market. He was increasingly supplementing the foods he purchased with foods he grew in the garden he installed in front of his house. When we spoke, he was at the end of the second season of growing his own food. This was a move he would not have made except for health reasons. Unlike the image of the young, bearded male urban farmer, Michael did not rip up his front yard by choice. For him, it was a necessity for staying alive – an antidote to “being hungry.”

Michael’s relationship to food was, to put it mildly, strained. Cooking and eating contained little pleasure. It was, rather, a mechanical fact of existence to be planned, undertaken, and endured. He could no longer simply walk into a grocery store and buy what he wanted for dinner; he had long ago lost the ability to eat out at a restaurant with friends or family. He mourned these facts of his life. The alternative to convenience foods was a labor-intensive process: traveling to two small markets and a farmer’s market to buy food in a city plagued by traffic and sprawl, digging up his front yard to create a garden when he was already so weak that he could no longer work, cooking bulk meals from scratch to create his own version of convenience foods for when he was too sick to prepare food for himself. What might seem to others his age to be the realization of an urban bohemian fantasy of self-sufficient, clean eating was, for Michael, a nightmare.

Unlike Michael's description of his no-frills kitchen with boxes of raw vegetables scattered on the floor, kitchens in which allergens and safe foods are co-present are arranged with extra precision. Those households that allow allergens in the home use highly elaborated systems to maintain the purity of food for members with allergies. In many families, only one member of the family has allergies, or different individuals are allergic to different things. Once foods which pose a danger to someone in the household enter the home, they are clearly labeled. Sometimes allergenic foods are indicated by adding a colored sticker to the package. Other times they are kept on a dedicated shelf, which may itself be indicated with colored tape or caution tape. The opposite strategy is also used: some families create a dedicated safe shelf, where all foods that are absolutely safe for the allergic person are stored in a single cabinet and foods outside that area cannot be guaranteed to be safe. Such systems take constant work to maintain. Careless mix-ups can lead to allergic reactions, and families are constantly aware that the stakes are high.

A cottage industry of advice columnists and professional organizers has sprung up to help people design allergy-safe kitchens. The Fall 2014 issue of Allergic Living magazine, for example, included a seven-page feature article about designing an allergy-safe kitchen, titled "Kitchens That Cook" (Van Evra 2014). "Allergy-safe" in this article went beyond just designing for food allergies. The materials they recommended were as "natural" as possible – made of wood, stone, and glass – to ostensibly reduce the possibility of volatile organic compounds (VOCs, found in higher proportions in plastics) off-gassing into the home and irritating asthma or chemical sensitivity symptoms. The top-of-the-line design included hardwood floors, low-VOC paint, wood cabinets, and glass- and stone-based countertops. Cabinets were spacious and plentiful to store the wide array of kitchen tools and basic grains, flavorings, and vegetables needed to cook all of a family's meals from scratch with ease. The size and abundance of cabinets would also make it easy to sort, see, assess, and choose the right products for different members of the family, whose nutritional needs might vary. Reading the article, I coveted such a kitchen. It was suburban luxury masquerading as medical necessity – the highest (and financially costly) expression of the hygienic sublime.

In a food allergic life, the heightened standards of order and purity sold to food allergy families as a solution to their health problems dovetail smoothly with the American middle-class fantasy of the home as a well-oiled and aesthetically-pleasing machine. Ruth Schwartz Cowan (1976) and Ronald Kline (1997) both reveal the origins of key dimensions of this fantasy in their historical studies of the rationalization and industrialization of the home. Kline's work on the problematization of "Country Life" in the early 20th-century home economics movement shows how women were trained to conform with normative ideas about the use of time and space on the farm. Cowan's work connects the adoption of modern household technologies in the American home to the emotional significance of women's work in the home. These legacies persist in the home management techniques and the hygienic sublime ideology of contemporary food allergy families.

Other scholars have shown how the hygienic home ideology has historically shaped responses to environmental allergies. Carla Keirns (2003) connects marketing tactics surrounding allergy to the subliminal ideal of the mid-century American home as a zone of hygienic purity. Professionals including allergists, home builders, architects, and reformers "joined together to create a new aesthetic of absolute cleanliness" as a proposed solution to the condition (524). Gregg Mitman (2007) compellingly documents how early air conditioning manufacturers targeted allergy sufferers, promising a pleasant indoor climate in summer. Ads promised that cool air could be had (for a price) within the hermetically sealed modern home, keeping pollen away from those with susceptible constitutions. In the construction of a food allergy-safe home, the legacies of the domestic hygienic sublime and the optimization of household work unite to provide a set of compelling models for managing unruly food proteins. This union of disease mitigation efforts with a hygienic aesthetic in the mid-20th century has antecedents in the sanitation movement of the late 19th century and the progressive era. The "ecological" (Anderson 2004) orientation of sanitarians, and indeed of much of 19th century medicine, demanded that attention be paid to maintaining and improving the "health" of environments (Valencius 2002). Visual and olfactory cues – the absence of waste and the smells of decomposition – were important indicators. Despite the shift of American medicine toward a microbiological understanding of infectious disease that sought to exclude, and later find and destroy, microbes, sanitation (and the aesthetic it promulgated) persisted as an important pillar of public and individual health (Leavitt 1992, Tomes 2000, Platt 2004). Its persistence in theories of home management provides grounds for the excessive expectations set forth by the allergic hygienic sublime.

The hygienic sublime offers a synthesis of the promise of purity and safety with middle class aspirations of appropriate social relationships, safety, and comfort in the home. Maintaining purity is a constant concern for people living with food allergies for good reason: an unexpected encounter with allergens *can* trigger an allergic reaction, and for some individuals allergic reactions can cause serious bodily harm, even death. When keeping one's home and the foods served within in it are the best form of medical care, the moral imperative for mothers to engage in unrecompensed care work in the sublime space of the home becomes stronger than ever. The ideal food allergy home – well-organized with inputs carefully policed – bears a striking resemblance to the well-run technological home promoted to American women homemakers since the early 20th century. This is a home that is organized around a gendered division of labor and arranged to foster the proper social reproduction of productive workers. The economic context for family-based care has shifted significantly since the 20th century, however. In the context of American middle class life, where a decades-long slide in wages makes it harder than ever to meet basic needs let alone seek upward mobility, there is little room for both taking care of kin and living a life of material comfort. Few families can afford to have one parent at home full-time; Alice and Michael count themselves lucky to have that luxury. Food allergy families therefore often must turn to an array of surrogate providers, such as restaurants and packaged food manufacturers, posing challenges to those industries to live up to the hygienic sublime as well.

## Domesticating Chefs

For food allergy parents, every meal their food allergic child eats presents a potential physical hazard. It is their responsibility to use proper food preparation strategies to minimize this hazard and create "safe" food for their child. Restaurants, by contrast, are businesses aiming to sell a carefully designed product and aesthetic experience. Their moral responsibility to protect customers typically only extends as far as the health codes that dictate the steps they must take to keep customers safe from pathogens and spoiled food. These standards are not (solely) upheld out of a sense of moral duty, but of fear of fines and other legal sanctions. But the needs of food allergic diners are different from those of the rest of the public. Ordinary food safety simply doesn't take their needs into consideration. Instead, heightened standards of purity must be produced materially and ideologically through the enactment of the hygienic sublime.

This section presents one entrepreneur's efforts to reconcile the mismatched conceptions of the moral duty to protect kids with food allergies held by food allergy parents and restaurateurs. The entrepreneur, who I will call John, is the founder of a company that runs a restaurant ratings and review website and trains food service professionals to consider the needs of people with food allergies. John is blunt about the fissures between food allergy parents and restaurants: parents want to protect their kids and restaurants are businesses that need to make money. His work aims to practically bridge this gap in order to make it easier for families with food allergic kids to eat out. Running the company is also an ideological project: John has set himself the task of single-handedly changing the way that restaurants serve people with food allergies. He is inscribing a vision of the allergic hygienic sublime into the assembly line restaurant kitchen. The moral economy (Thompson 1971) he proposes to do so is strikingly implausible (not least because it is practically difficult to implement), yet it rests upon a financial logic that is rigorous by the standards of business consulting. His forthright perspective on making an economic case for the moral duty to protect people with food allergies is unique in the public discourse of the food allergy world, yet emblematic of the widely shared sense that companies ought to take their needs into account.

I first heard about John's work via his blog, and I reached out to him directly when I found out that his company was putting on a day-long conference for restaurateurs in my city. I attended the conference, taking notes on each presentation, sharing lunch with participants, and chatting with him briefly at the end of the day when we were both available. Several weeks later, I interviewed John by phone and heard the origin story of his venture. His background was in finance and consulting, specializing in helping chain restaurants grow and expand. In 2006, he found himself in charge of his three sons while his stay-at-home wife was out of town. Trying to feed all of his children – working around both preferences and food allergies – was a tougher task than he had realized. All decisions about what to eat had to be made with the needs of his middle son's multiple food allergies in mind. He left his corporate job in 2008, after this incident, seeking a change of pace and armed with the idea that he could take on a new project to help families like his own who were living with food allergies. He quickly put his networking and research skills to work, bouncing ideas off of staff at a prominent allergy and asthma non-profit organization. Eventually he settled on the idea for a restaurant review platform targeted at families managing food allergies. Sensing continued interest in the idea, he put the pieces in place and began his company in December 2009.

Restaurants are, by and large, out of the question for families with kids with food allergies. Eating in a restaurant removes control over food preparation from parents and gives it to chefs. Food allergic people and food allergy parents typically do not trust anyone other than themselves to prepare food for themselves or their children. Although they generally trust that kitchen workers in commercial kitchens are qualified to prepare foods that are free of pathogens and made with reasonably high-quality ingredients to the same extent anyone else does, they do not trust that they have adequately deep knowledge of allergies to prevent cross-contamination or look for "hidden allergens" in ingredient lists. They assume staff in commercial kitchens know less about cooking around allergens than they do. According to John, this assumption is correct. While researching his business plan, his discovered that "no one else had been in both food allergy and restaurant worlds." Food allergies are typically not high on the list of concerns for restaurants. Given his experiences in the restaurant industry and with his own food allergic children, he realized this was a niche he could fill.

In our conversation, John explained the situation from a restaurant's perspective, drawing on his years of work consulting for big players in the industry. The restaurant business isn't about providing nuanced care to customers, he argued. It is, first of all, about making money, and in order to do so restaurateurs feel they must provide diners with a specific, reliable aesthetic experience. Teaching chefs to work around the needs of food allergic people requires a paradigm shift in thinking about what it means to eat in public that one has paid another party to prepare. The very idea inspires annoyance in many chefs and restaurant managers, since they typically have fixed ideas about what they want their food to taste, smell, feel, and look like. Swapping out common allergens like butter, wheat flour, or eggs can dramatically affect the aesthetic properties of foods, especially if they are done by cooks unaccustomed to making such substitutions. Cakes deflate, bread comes out too tough or crumbly, and pasta fails to reach a perfect *al dente* state. And when the food is poor, so is business. In the eyes of many in the industry, John reported to me, a restaurant's job is to provide an aesthetic experience that reliably brings enough customers through the front door to help the bottom line, not to provide proxy medical care to its customers by providing menus tailored to health conditions. In this conception of restaurant eating, food as care must happen in the home, not in a restaurant.

John uses financial logic to convince restaurateurs to take steps to accommodate food allergic diners, a common approach in the consulting industry. His standard pitch to restaurateurs, which I heard during a panel at his company's conference I attended and again during our interview, consists of a market analysis and a cost-benefit analysis. He focuses on the financial side because of his understanding of a restaurateur's point of view: "Everybody that does this [works with my company], they don't say, yeah, we do it because it's good for the community… I mean, some of them may actually start that way, but most of them are business people. They say, it's got to be good for business as well." His pitch seeks to demonstrate how extraordinary additional profits are possible by devoting comparatively tiny resources to equipment and training for kitchen staff that prepares them to handle the needs of allergic diners.

Here's how his pitch proceeds. He starts by offering a back-of-the-napkin market analysis. First, he assumes that roughly five percent of the American population is food allergic or has celiac disease, thus requiring accommodations in most restaurants. Ninety percent of these individuals are willing to dine out of the home – four and a half percent of Americans. Average restaurant parties consist of three people. The allergic person – like his middle son in his "aha!" moment story – will always serve as a "veto vote," nixing restaurants that can't accommodate them and shaping the dining patterns of their companions. Suddenly that four and a half percent of Americans who are food allergic and eat out becomes thirteen percent of the dining population whose decisions are shaped by food allergy considerations. Here, John rounds down to ten percent, a "conservative" number in his view.

Once he's laid out the demographics, John moves on to how this impacts the restaurant business, treating common industry business models as a given. A typical restaurant makes eighteen cents profit on each dollar at the point when it becomes sustainable enough to stay in business. Filling extra seats at that point – when no new staff or infrastructure is needed to scale up, only additional food – delivers fifty cents on the dollar. He rounds this to forty-three cents on the dollar. If there's a ten percent increase in sales at this margin, the restaurant's profits – what it makes after salary, taxes, supplies, utilities, and so on – are increased by twenty-four or twenty-five percent. This is, in John’s words, “tremendous” in the restaurant industry. An average restaurant doing $1.75 million in yearly sales would see its profit increase from $325,000 to $390,000, a $65,000 increase.

The final piece he explains is the investment in supplies and training needed to produce those profits. Training is key since, as John’s training in consulting drilled into him, “the priorities of the leaders become the priorities of the people.” He estimates that $500 would be needed for training and another $500 for supplies like separate toasters, utensils, and duplicate cookware. For a $1000 investment (here his numbers get fuzzy and his voice gets louder) you can see a 5,000% to 25,000% return. The numbers don’t add up, but his delivery emphasizes that the *scale* of return matters more than the *precise number*. Of course, he explains, getting the word out about what’s going on in the back end of the kitchen may take some time, so in the early years the return on investment may be a more modest 300%. Increasing profits by such a margin is particularly appealing in an industry where recouping the initial investment typically takes three to four years. “As long as you can attract the people,” John explains, “word will get out over time, [and my company] can help accelerate that.”

Switching back to a market analysis perspective to wrap up his pitch, John reiterates the central logic of his project: “If you become allergy friendly and you can cater to this audience that will now come to your restaurant that couldn’t before – not only didn’t they before, they couldn’t … you’re making a ton of money for such an easy investment.” He collects and occasionally posts quotes from famous chefs he works with – including Ming Tsai of Blue Ginger fame – when they make statements to this effect to promote his company. In the long term, the five percent of diners may become ten percent, which means thirty percent of dining decisions will be made taking food allergies into account. Five years from now, “early adopters” might have the market cornered, leaving no room for those who don't get on the food allergy bandwagon today. As he says, "there aren't many restaurants that can survive letting go of thirty percent market share." Luckily, his company is there to help them adapt.

John's use of financial language and business logic is self-consciously strategic in proposing a moral economic model for pushing restaurants to accommodate allergic diners. Economic historian E. P. Thompson defined a "moral economy" as an economy where moral concerns about the proper relations and responsibilities of categories of actors in society pushed back against strong economic trends:

> [G]rievances [of the English poor in the eighteenth century] operated within a popular consensus as to what were illegitimate and what were illegitimate practices in marketing, milling, baking, etc. This in its turn was grounded upon a consistent traditional view of social norms and obligations, of the proper economic functions of several parties within the community, which, taken together, can be said to constitute the moral economy of the poor. An outrage to these moral assumptions, quite as much as actual deprivation, was the usual occasion for direct action. (Thompson, 1971: 79)

In 2015, when John framed his company as providing a fiscal rationale to encourage restaurants to accommodate allergic diners, he instantiated not a "traditional" view of the norms and obligations of public dining, but a new view, one particular to the food allergy community and its political aims of fuller social inclusion for food allergic individuals. He believes (possibly rightly) that appealing to profits and business models will better convince restaurateurs to improve their procedures for accommodating food allergic eaters than appealing to their moral sensibilities. The business case proceeds with little mention of his own stakes in the game – the fact that getting restaurants to sign up with his review website or work with him in a consulting relationship is his bread and butter and will build his reputation in the food allergy, business, and food service communities.

These rhetorical maneuvers are necessary, he believes, because the idea of food as *medical* care is excluded from the logic of the commercial restaurant industry. I specify "medical" care because vegan, vegetarian, paleo, local, and raw food restaurants abound in American cities today, all catering to customers who believe that eating the "right" kind of food is a way to maintain and increase bodily health. These diets emphasize food as a tool for taking care of the body, too. However, the moral logic to these dietary patterns does not speak to the hygienic sublime but rather expresses ideas about the value of self-improvement and the perfectability of the human body. As in the food allergy world, there is an element of aspirational upward mobility to these self-imposed dietary restrictions: seeking the luxury to eat foods that are not associated with bodies that do hard labor, and foods that take aesthetic cues from traditional cuisines to demonstrate the eater's cosmopolitanism without carrying the stigma of backwardness or the "old country." These are also distinctly American ways of eating and of relating to one's food in the twenty-first century.

It is ironic, in this landscape, that diners whose eating needs are shaped by a *diagnosed* medical disorder – food allergies – have a difficult time securing necessary accommodations. Many food allergy advocates place at least some of this blame with adherents to optional specialty diets. They fear that the "pickiness" of some diners inures servers and restaurant staff to the life-or-death stakes of serving people with food allergies. The most memorable moment where these concerns came to the fore followed a post by "Food Babe," food blogger Vani Hari, to her blog. In the post describing her recent trip to Italy, titled "Food Babe Travel Essentials – Eating Outside Your Home!" (2011), Hari encouraged her readers to stick to their GMO-free, organic, healthful diets by claiming to have a food allergy: "Go as far as telling the server you allergic to butter and dairy, soy and corn. Butter really isn't bad for you if it is organic and you use it in moderation – but restaurants can go crazy with it adding several hundred extra calories you can live without."

Food allergy bloggers regularly respond to statements like these with vitriolic responses. Food Babe in particular is an avatar for irresponsible food allergy politics and a subject of contempt. A characteristic response to the "food allergy fakers," written by Lane Moore (2014) for *Cosmopolitan*, summed up the community feeling with passion:

> But saying you have an allergy, while everyone knows you don't have one, just puts me on trial every time I have to tell someone. I have to justify it, draw up documents, prove I'm not just being an uppity asshole. I have to convince waiters, who will often lie about the ingredients in foods and tell me my allergens aren't in there when they are, and then I end up vomiting all night or with a fully body rash or my throat swelling up like it's full of golf ball-size grenades. Basically, I have to prove I'm not like you.

Moore points out that when restaurants fail to respond conscientiously to her needs, she gets ill, whereas others who claim to have allergies, in order to stick to their dietary preferences, suffer no ill consequences. The fear among people with food allergies is that when the "liars" survive despite the kitchen's lack of attention to their needs, the reality of food allergy is undermined. Staff let their guard down, allergens get into dishes where they do not belong, and allergic people like Moore become ill.

What is unique about serving diners with a diagnosed condition is that the restaurant is potentially legally liable if they make a mistake with the order and serve food that injures or kills a patron. Indeed, a handful of suits have been filed against restaurants in recent years concerning this very issue, including one suit against a Minnesota restaurant that served a milk-allergic boy pancakes containing milk, killing the child, and a grocery store in Alabama that served a nut allergic boy a chocolate chunk cookie that contained walnuts (Nath 2015). Restaurants and other food service providers must take the word of allergic consumers at face value. If their vigilance slips, due to an honest mistake or out of skepticism concerning a customer's requests, they run a significant moral and legal risk.

Some restaurant staff react by lumping all allergens together, instead of appreciating that there is a wide variety of allergens that commonly trigger reactions and that any individual could be allergic to a different combination of foods. Gluten intolerant (and thus wheat-avoiding) blogger Celia Kaye (2014) reports such an instance: after hearing about her dietary restriction the server declared that all of the desserts, even the ones that did not contain wheat, “all have something.” He elaborated, “We don't want you to get sick or anything,” suggesting that the ice cream, crème brûlée, and sorbet would be off-limits to her. Kaye points out the absurdity of his declaration with humor, writing:

> Nuts, dairy, eggs, wheat -- there was no distinction. Even if I wanted to get on the train to wheatless land, tottering along the tracks with a big bowl of ice cream and wet walnuts, I had to go to wheateggsnutsdairyless land instead. It didn't matter that the ice cream was actually gluten-free, because somewhere, someone couldn't have dairy, and the ice cream was placed on the "allergenic" list.

Thus, even when aesthetic objections to serving food allergic patrons are proven unfounded through the efforts of someone like John, risk management practices can still make dining complicated for both staff and customer. In some cases, limited awareness of the needs of allergic diners results in paternalistic control, rather than the intended careful review of restaurant practices.

The financial logic of John’s pitch takes this into account by acknowledging the costs of training and supplies necessary to serve food allergic diners and by proposing financial benefits so enticing as to make the risk of liability pale in comparison. He reported that restaurants that take up his challenge cite the financial benefits as a primary enticement, and later report to him that they are pleased with the relative ease they have with implementing the training and techniques necessary to become allergy-friendly. Restaurants show they care about food allergic diners as a byproduct of their business strategy; this special company-customer relationship is then used as the business’s calling card to draw more business from food allergic people. The financial incentive of accessing the allergic diners market is enough, in John’s estimation, for them to put in place the key practices of substitution, strategic cleanliness, and separation. Like home cooks and kitchen designers, they are pursuing the enactment of a hygienic sublime in which the pursuit of purity is imagined to ensure safety. In the restaurant setting, attaining this status would, in theory, ensure protection from legal liability for harm as well as an aspirational future of ever-increasing profits.

## Trust in Brands: Rethinking Safety in Industrial Food Production

Alongside restaurants and the home kitchen, a handful of specialty food manufacturing facilities have become a site for the enactment of the allergic hygienic sublime as well. Much as many people living with food allergies would like to take Michael’s approach described earlier – growing their own food and buying food directly from farmers – the practical constraints of modern American life make this impossible for most of them. Instead, many food allergy households rely on processed convenience food just like their non-allergic neighbors. A number of food companies have emerged in recent years which seek to solve the social and practical challenges of living with food allergies by offering food allergy friendly products. Rigorous hygienic practices on the factory floor and intensive supply chain management make their products exceptionally traceable and set them apart. Products are offered at a premium price but come with the promise of enhanced safety, backed up by an image of the manufacturer as trustworthy and caring – yet another example of the moral economy of providing food to food allergic customers. To increase their potential market share, specialty food companies often cater to people with a range of specialized diets, which may be medically necessary or part of a lifestyle choice, and often make similar promises concerning purity and safety for both kinds of audiences. The remainder of this chapter will analyze the work that one such company does to provide “safe” snack foods and casual meals to food allergic consumers. For this sector of the food industry, the hygienic sublime is both their moral purpose and the key to their profitability.

A highly successful company that exemplifies this kind of corporate care work in the food allergy world, which I will call Company X, is based in a metropolitan area in the Midwestern United States. I interviewed a staff member in the marketing department to learn more about the company and its philosophy. Company X was founded in 2002 by two friends in business school in the same area as the company’s current location. One of the founders had watched his mother take up a gluten-free, casein-free diet (that, is a diet free from wheat and related grains and all milk products) to manage her multiple sclerosis symptoms. Originally named after their university mascot, they soon changed the name to include reference to the name of the founder’s mother, who was chronically ill with an autoimmune disease and had to adhere to a special diet. Around the same time, the FDA defined the top 8 allergens: fish, shellfish, peanut, tree nut, milk, wheat, and egg. The company was founded with the mission to exclude all of these ingredients to make it as accessible as possible to people with common food allergies and other dietary restrictions.

Company X’s philosophy is summed up by its internal motto, “Taste, Trust, Love.” (Their consumer-facing tagline, at the time of this writing in 2015, is different: “Eat Freely.”) According to the marketing professional I spoke to, “if consumers don’t feel those three things when they eat or see our products somewhere, we’re not doing our jobs right.” She defined trust as “someone sees our logo and they don’t even have to read the label and they know they can eat the product.” To build this trust, the company rigorously manages all potential sources of contamination risk. Following a forensic logic of risk management (discussed at length in the previous chapter), their materials and supply chain are precisely documented, and ingredients are tested for off-limits substances before they are off-loaded from a delivery truck into a production facility. Employees at the company headquarters and factory floor are treated as potential sources of risk as well, and they are consequently rigorously managed to prevent contamination as well. Peanut butter sandwiches, for example, are banned from the building, even the break rooms. Televisions in the break room of factory floor workers play video loops reiterating the floor rules and mission of the company, embedding risk mitigation practices into the background noise of company “culture”. A great deal of behind-the-scenes work goes into making the company trustworthy, driving its moral-economic function.

This company is not alone in cultivating relations of care and trust with their customers. Recent ethnographic work has documented and critiqued the affective strategies of corporate social responsibility (CSR) programs developed by multi-national corporations (Welker 2009; Shever 2010; Dietrich 2013). Shever, Welker, and Dietrich, working in different regional contexts, launch similar critiques of CSR programs, arguing that building “trust” in the contexts they study merely opens the door for more intensive exploitation of local populations by hegemonic multi-nationals. Feminist sociologist Juliet Schor (2011) takes a similarly critical view in her commentary on the imposition of corporation advertising messaging on childhood in the United States. She argues that “corporations increasingly have been acting as parents” since the second half of the twentieth century, taking on the role of caretaker, moral trainer, and material provider (211). Their increasing prominence in family life fills a gap created by the busyness of households in which both parents work, squeezing the hours traditionally devoted by parents (usually mothers) to child care work. To Schor, this state of affairs is reprehensible.

Food allergy families are not immune to these corporate machinations, but they interpret them very differently from critical social analysts. For them, particularly for the mothers who are in charge of caring for food allergic children, ceding some of the care work to corporations is a way to ensure social integration and to keep up with the accelerating treadmill of American life. Food allergy mothers often mourn their child's exclusion from popular foods and food-based rituals. Exclusion from consuming store-bought birthday cakes and mass-produced tubs of ice cream at birthday parties is particularly troubling. In interviews and encounters at food allergy events, my interlocutors fret about whether their children feel excluded and whether opting out of participating in birthday parties will preclude the formation of age-appropriate friendships in general. A secondary concern – especially for mothers who do or hope to work out of the home – is that they have lost access to the time-saving technology of pre-made, packaged food. Balancing a job, a partner's schedule, and multiple children's activities is much harder when health dictates that most canned soups, frozen dinners, and locally-available drive-through or fast casual meals are off-limits. The work of trustworthy specialty food companies is deeply appreciated by these families, especially those with younger children, because it allows them to feel as though they can participate in and provide a "normal" childhood experience.

I witnessed firsthand how Company X enacts trustworthiness during a tour of their factory in 2014. The tour, my first encounter with the company and their philosophy, was offered as an add-on to a food allergy conference held near their headquarters. A friendly, blond young woman, dressed in the smart start-up uniform of well-fitting jeans and a blouse, led the 20 or so tour participants into a small conference room. We put on lab coats and hair nets to protect and dramatize the hygiene of the food processing plant we were about to enter. Meanwhile, she recounted the company's origin myth and their top-8-free philosophy. She detailed the steps involved with sourcing ingredients such as cinnamon, including the research and networking it takes to identify producers who trace the movement of ingredients closely enough that they can guarantee their products have not come in contact with common allergens. Preamble over, she led us into the factory, pointing out the special fifty-pound crates of uncontaminated cinnamon, as well as buckets of nut-free, dairy-free oils and proprietary wheat-free flour mixes. We peered into industrial mixers as she described how they were broken down and cleaned between manufacturing different products to standards that were much more exacting than legally mandated. At the end of the tour, we were led into a converted hallway where, our tour leader informed us, purity tests and taste tests were conducted side by side. Every batch was tested for purity, exceeding once again the standards of the law and of other companies and duplicating the detective work that had previously gone into sourcing the raw ingredients which had by that point been transformed into tasty treats and cereals.

*Figure 2. An anthropologist visits a specialty foods company.*

Offering a detailed look at the factory floor demonstrated the transparent nature of Company X’s commodity chain. This enactment was understood by the company to be an important component of building trust with food allergic parents and adults, all of whom learn, at one point or another, that they ought to investigate the provenance of foods manufactured outside of the home to eat safely with food allergies. The tour functioned as a marketing tool, to be sure, but one underwritten by a logic of risk management tailored to the demands of the US food allergy community. Research, transparency in sourcing, and laboratory tests for purity were all on display. In making their case that their ingredients were low-risk due to rigorous sourcing and monitoring, they enacted a version of the hygienic sublime that was specifically geared toward driving the engine of the moral economy of food allergy friendly specialty food sales.

*Figure 3. Safe cinnamon awaits processing on the factory floor.*

STS scholars have long been interested in the social consequences of demonstrations of technical expertise. Bruno Latour set the stage with his now-classic work on Louis Pasteur's work to demonstrate the existence of microbes to the public – "outsiders" to the laboratory spaces and scientific epistemology that gave shape to Pasteur's research (Latour 1983). His proto-“sociology of translation” (Callon 1986) approach stresses how the movement of people, microbes, and knowledge between French laboratories and farms created an interested public (and also clients) beyond the community of French scientific experts. Demonstrations of the vitality of anthrax microbes and the efficacy of inoculation in the laboratory were made to extend out into the world through subsequent field experiments. By carrying out this sequence of experiments and broadcasting their outcomes, Pasteur positioned what happened in the laboratory as a valid model for what happened in the field. Pasteur’s carefully controlled series of translations between lab and world constructed microbiology as a publicly credible domain of science, and one with the capacity to answer questions about the causes of and solutions to disease. Other scholars have also documented how credibility may be garnered by having affiliations with institutions deemed credible and trustworthy (Wynne 1992). Wynne reflects that “public responses to risks and risk information are rationally based upon their experience and judgment of the credibility and trustworthiness of the institutions which claim to be in charge” (p. 281). Demonstrations of this sort – whether through institutional affiliations or through trust-making practices – are particularly salient in contexts in which human health is at stake (Epstein 1996).

As with Pasteur’s microbes, there is nothing intrinsically interesting about the factory floor of a food manufacturing company to the outside world. Yet food allergic people and caretakers have learned, often through trial and error (eating a food and becoming sick), that they ought to be interested in what goes on in that space. Food allergy education via support groups, informal networks, and advocacy organizations have also been a major vector of this type of information. The food allergy public, thus interested in how their food is made, seeks out information by reading labels, calling food manufacturers, and building relationships with local farmers. Company X’s factory tours address these concerns and offer people living with food allergies an insider’s view of their production practices and supply chain management to publicly demonstrate their trustworthiness. Company X hopes that consumers will automatically associate their brand, and by extension their products, with minimal risk of contamination with top eight allergens. Their enactment of the hygienic sublime through the maintenance of pure ingredients and factory floor hygiene thus serve an important practical function – to protect their consumers – as well as providing the raw materials for a moral economy of food allergy-friendly goods.

The technical claims that Company X makes in its quality control procedures exceed industry standards, making them an exemplar of food allergy-friendly practices. Scientific evidence suggests that vigilant exclusion of allergens below certain levels ceases to provide additional protection. The clearest scientific evidence for a baseline safety level for allergen contamination comes from a 2013 FDA report on research on immune responses to wheat gluten protein. This research and report were, in fact, mandated by the 2004 FALCPA legislation, though it took nine years instead of the amendment’s recommended two to come to fruition. The review, carried out as part of a process to set new standards for the requirements to be met for food labeled “gluten-free,” notes that concentrations of gluten below 20 parts per million (ppm) cannot be reliably measured and have not been demonstrated to consistently provoke immune responses in those with wheat allergy and Celiac gluten sensitivity (Food and Drug Administration 2013). In light of this report on gluten sensitivity, many food allergy advocates and specialty food manufacturers expect to see 20 ppm become the level for all claims of allergen-free status (for example, peanut-free or egg-free). But this 20 ppm level is not considered “safe” by many in the food allergy community, especially mothers of allergic kids who have seen their children have unexpected reactions to supposedly safe foods. In the view of my contacts in the food allergy world, the FDA’s claims seem to imperfectly account for the sensitivity of allergic bodies. Rather than test *post-hoc* for the presence of allergens, the community consensus is that rigorous prevention of contamination is the safer option.

Company X, eager for their business and morally committed to serve them, seeks to deliver the levels of purity that potential food allergic customers consider unquestionably safe. The company holds its suppliers accountable to a more stringent standard than the FDA requires for gluten-free labeling. Rather than relying on testing to the 20 ppm level alone (for gluten as well as other allergens, which already extrapolates the standards to a different domain), they also require complete documentation from suppliers that at no point was there the potential for ingredients to have come into contact with top eight allergens. Their transcendent standards attempt to instantiate the hygienic sublime – a state of absolute, documented purity of their raw materials and finished products. Yet whether or not “absolute” purity has been attained will never be knowable, since the reliability of testing instruments is in doubt below 20 ppm. The reliability of documentation is also always open to question because allergenic substances do not always respect human expectations of their agency (Mitman 2007).

The quest for pure food made by reliable producers among people with food allergies coincides with increasing interest in food purity and provenance more generally in the United States. The artisanal cheese sector, about which anthropologist Heather Paxson (2012) has written eloquently and extensively, is emblematic of this cultural fixation. The careful cultivation of microbes imbues artisanal cheese with a sense of place and tradition. The intimate knowledge of process, place, and product that producers gain through experience is, they claim, also a foolproof way to improve the safety of the final product. That is, producers claim that their expertise satisfies both the ethical and aesthetic desires of consumers and the safety logics governing the US food supply. By contrast, the foods that Company X produces are highly processed and include ingredients from around the world. Placefulness and affective intimacy between producer, process, and product is not required or assumed. However, a kind of *technical* immediacy is maintained: ingredients are identified as purely what they are down to the parts per million through careful monitoring of the supply chain and laboratory testing of ingredients as they arrive at the factory. The company's presentation of managerial and technological proficiency forms the basis for moral claims about the safety of Company X's food and their commitment to consumer wellbeing. It enacts the company's internal motto: "taste, trust, love."

What makes the highly processed allergy-friendly foods made by Company X valuable to food allergic consumers is the company's rigorous approach to supply chain management. Anna Tsing's (2013) notion of "supply chain capitalism" is instructive for understanding the power of this business strategy. In Tsing's ongoing study of human-human and human-non-human relations generated by the transcontinental matsutake mushroom trade, sorting and re-sorting the mushrooms as they move from one link of the chain to the next is a way to negotiate their status as gift and commodity. Unlike those who trade and gift matsutake, Company X does not purport to "gift" their product to their consumers, and their product does not have traditional value as a gift for friends and colleagues. Nor do they suggest that their ingredient suppliers provide verifiably pure ingredients solely due to a sense of social obligation. However, the very fact of *having documented and verified* the provenance of ingredients, of having consulted with suppliers up the chain as close to the raw ingredient source as possible, lends their products special value. Attending to the supply chain in detail shows that the company cares about ensuring the health of their food allergic customers.

Company X’s particular enactment of supply-chain capitalism has made them a major actor in the food allergy community in the United States. They are recognized as an industry leader in the food allergy-friendly food sector, with company representatives speaking at food industry and patient advocacy conferences across the country. They sponsor events and programs for a number of non-profits, some related to food allergies, some related to other conditions managed through diet, such as celiac disease and autism, and some that develop the tests they use to police their supply chain. These activities have lent the company additional moral authority in the community. They are also a distinctive component of their particular embodiment of the allergic hygienic sublime: not only are their foods pure, above and beyond available standards; not only do they open their factory to build trust with consumers through demonstrating this purity; but they also participate in the food allergy community as a quasi-citizen, contributing to programs that increase their visibility, put them deeper into conversation with food allergy families and advocates, and improve their technical proficiency.

*Figure 4. Chocolate treats fresh from the oven.*

Yet, as of February 16, 2015, the company's moral authority is potentially in crisis. On that day, Company X announced that it had been acquired by a division of a global food conglomerate. This was especially ironic because, in my conversations with people in the food allergy community, the company that acquired them often stands in as the stereotypically secretive, uncooperative food producer. The social media backlash was intense and immediate, with mother-activists tweeting directly at Company X's Chief Marketing Officer to express their disappointment with the move. In keeping with his persona as an accessible and responsive executive, he responded directly to many of the messages in the first hours after the announcement, assuring critics that the company would remain an independent division within the larger corporation. It would, importantly, retain the authority to manage its own supply chain. The move, as the press release announcing the change reported and the CMO reiterated, would "combine our great brand, market leadership and passion for our consumers with the global resources, scale and marketing expertise of [multinational company]." In other words, giving up ownership of the company would allow it to scale up its supply chain management while accelerating its growth. Company X's instantiation of the hygienic sublime, like the capitalist system in which it is embedded, seeks expansion, intensification, and acceleration while continuing to promise purity and safety to consumers.

### Mastering the Hygienic Sublime: Purity, Ontology, and Capitalism

Eliminating foods from the diet, especially basic ingredients like wheat, dairy, eggs, and soy, is a difficult task, calling into question standards of food purity and transparency in the American food system (which is increasingly international). Creating "safe" foods to replace staples takes place in the home, in restaurants, and in the factory – yet each setting demands different techniques for producing and demonstrating safety, producing different enactments of the hygienic sublime. In the home, people managing food allergies produce safety through the intensification of ordinary domestic techniques. Restaurants, by contrast, are figured as purely profit-making spaces, requiring cost-benefit-based arguments to accommodate allergic diners. Companies seeking allergic consumers police their products using careful supply chain management and laboratory tests on the factory floor in order to produce demonstrably allergen-free foods. Food allergic people draw on all of these sources of safe food as they go through daily life with this chronic condition. At stake across all of these contexts is the fact that a diet tailored to an individual's particular allergies is the best medicine for people with food allergies.

On the surface, the categories of "safe" and "unsafe," "pure" and impure," appear to be merely descriptive of the (potential) material properties of foods. This looks like an ontological problem, one where the competing politics of care and food production must be brought into agreement at least temporarily (Langwick 2011) or choreographed (Thompson 2005) to allow for the activities of everyday life to proceed as necessary. Like everything in the food allergy world, what is most notable about these ontological categories is their moral significance. Since eating an impure food product or trusting the wrong food manufacturer has the potential to lead to serious illness or death, policing food preparation is often seen as the front line for preserving health and warding off death in the food allergy community. Proper enactment of the category "safe food" is of vital importance.

The "hygienic sublime" is the term I use in this chapter to refer to the highly choreographed practices, demonstrations, and rhetoric that enact this category of "safe food" for people living with food allergies. The hygienic sublime encompasses these practices, the logics that motivates them, and the ideal of absolute safety and purity that may never be reached but must always be sought. Like David Nye's "American technological sublime," the hygienic sublime is suffused with American aspirations of progress and pursuit of the Good Life. For individuals and families managing food allergies, the condition presents not only an existential threat to the body of those with allergies, but also a threat to the attainability of a wholesome American childhood and "normal" social life. There is plenty of room to critique this pursuit, yet with anthropological sympathy I recognize that these families are caught in what Kim Fortun (2001) calls a "double bind." My interlocutors, and the food allergy community at large, live within "fields of force and contradiction" that make every eating decision a trade off (p. 11). The time it would take to perform the domestic labor of preparing foods from scratch at home is time that cannot be spent in remunerative labor that is needed to buy the foods in the first place, or in social activities that may ensure proper social reproduction. But the very same complicated and secretive food production practices that make tracing ingredients and their origins difficult in the first place also offer the promise – when intensified – of producing safe foods which promise to take time pressure off squeezed mothers and families.

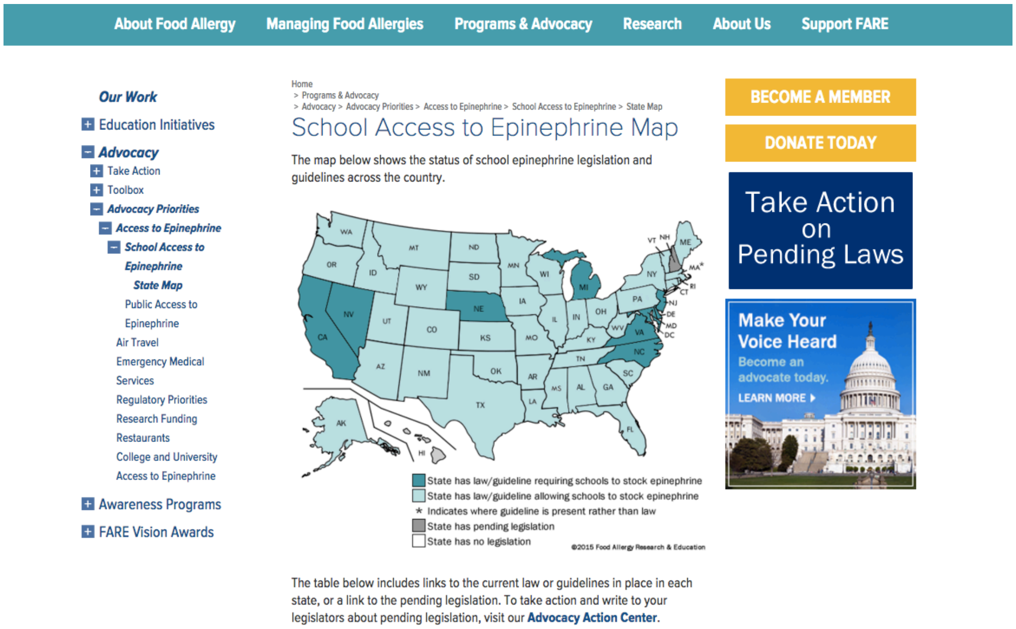
That intensification is, perhaps, characteristic of life as an eater in America, where food and eating are caught up in capitalist endeavors. Capital, as Marx (1976) observed, demands ever-increasingly returns, which require ever-intensifying methods of production. At the heart of the hygienic sublime we find this logic lurking. The intensification of food production created the problem, but further intensification offers a solution. Intensifying the moral connotations and ordinary practices of domestic labor, including caretaking and food preparation, proves to be a way to ensure the safety of food allergic children and adults. Can the answer to the problem of a globalized, ever-intensifying food system emerge from within the system itself, and using its native techniques of supply chain management, loose regulatory oversight, and financial logic? My observations of the food allergy community reveal that such a solution continues to depend on problematic, traditional gender relations and a conservative moral order. Yet, as this chapter and the next show, this is an ordering of society that is productive of new ways of thinking about illness and the responsibility of both private industry and the state to provide care for those who need it.

A double bind indeed.

## CHAPTER 6

# ADVOCACY, DISABILITY, AND THE LAW: REDISTRIBUTING RESPONSIBILITY FOR FOOD ALLERGY CARE

On November 13, 2013, president Obama signed into law the School Access to Emergency Epinephrine Act to encourage states to enact legislation making epinephrine auto-injectors more accessible in public schools (Solomon 2013). The voluntary act encouraged those states that didn't have stock epinephrine laws – laws that allow or mandate epinephrine auto-injectors to be available for anyone's use in certain public places, most often schools – to develop them, and those that had them under consideration to quickly enact them. It dangled a carrot in front of state legislative bodies, promising states with such laws preference for certain medical research funding, including the Children's Asthma Treatment Grants Program (Jarrett 2013). While signing the bill, Obama indicated his own connection to food allergy, revealing that his daughter Malia had been diagnosed with peanut allergy. The federal bill was, in the President's statement, "something that will save children's lives" – the children of America, including, potentially, his own child. To many in the food allergy community in the United States, the successful passage of this legislation signified the growing public recognition of the food allergy "epidemic." It was understood to be an important win for food allergy activists, advocates, and parents battling for more social support for managing the condition. By August 2015, the only state without legislation pending or enacted was New Hampshire (FARE 2015b).



Home
> Programs & Advocacy
> Advocacy > Advocacy Priorities > Access to Epinephrine > School Access to Epinephrine > State Map

School Access to Epinephrine Map

The map below shows the status of school epinephrine legislation and guidelines across the country.

▨ State has law/guideline requiring schools to stock epinephrine
☐ State has law/guideline allowing schools to stock epinephrine
* Indicates where guideline is present rather than law
▨ State has pending legislation
☐ State has no legislation

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The table below includes links to the current law or guidelines in place in each state, or a link to the pending legislation. To take action and write to your legislators about pending legislation, visit our **Advocacy Action Center**.

*Figure 5. FARE’s “School Access to Epinephrine Map,” indicating state action concerning stock epinephrine in schools legislation.*

The struggle for and effects of social and institutional recognition of chronic illnesses has been examined by other science studies scholars (Rabeharisoa and Callon 2002; Callon and Rabeharisoa 2003; Epstein 1996). What is clear from the work of such scholars is that it takes a considerable amount of choreography among the participants in a debate about the nature of a medical issue to establish a medical state or condition as one kind thing and not another, a process that simultaneously shapes the actors involved, the category itself, and the things or people to which it applies (Thompson 2005). These ontological and political questions have significant consequences for how patients live with their conditions, and how they relate to others in the process (Mol 2002, 2008). Among parent advocates, a common goal of activism – in both public, institutional settings and in private, interpersonal interactions – is to minimize the isolating social effects of the condition for children (Blum 2007). Cheryl Mattingly goes even further, suggesting that there is not only a question of *what to do* in anticipation or response to medical crises in children with disabilities, but also, and always, a question of what to do *to attain "the good life"* (Mattingly 2014b). The case of food allergies illustrates that ontological questions about what a disease is, pragmatic questions about how to live safely with a disease, and moral questions about what a "good life" with chronic disease ought to be are deeply entwined in the lives of families managing long-term medical conditions.

Patient activism has been a latent theme throughout this dissertation, and in this chapter, I will look more closely into the way responsibility for caring for people (especially children) with food allergies is enacted in the legislative realm via stock epinephrine bills. This advocacy project is deeply moral: it seeks to reframe who can, and who ought to be, responsible for taking care of people with food allergies. At stake in advocacy rhetoric about epinephrine is what Sarah Lochlann Jain (2006, 24) calls "a politics of sympathy" – maneuvers to align claims of injury, rights to bodily integrity, and legal mechanisms that assign blame for harm. Food allergy legislative advocacy initially focused on bills allowing or mandating stock epinephrine in schools, but more recently advocates and organizations have begun backing "entity" bills, which allow a wider variety of entities (like summer camps, shopping malls, and restaurants) to keep stock epinephrine on hand. Stock epinephrine bills are positioned as a tool for changing how society regards people with food allergies as well as a practical resource for ensuring their safety. People advocating for such laws seek to treat food allergies less as the responsibility of individual patients and families and more as the collective responsibility of the communities in which they live.

Put another way, stock epinephrine advocates are attempting to enact the core lesson of disability scholarship and activism: disabling conditions that an individual experiences are not intrinsically limiting, but become so in the context of social structures and practices that do not adequately accommodate people with a particular bodily condition. Proponents of the "social model of disability" argue that it is this discrimination or lack of consideration that limits opportunities in life and threatens safety, not the condition itself. As Tom Shakespeare (1996: 96) writes, among disability scholars and their activist allies "disability has been conceived as an outcome of social processes or as a constructed or created category."

This conception of disability has been taken up and reworked by scholars from a wide variety of fields who share concerns with how identities are instilled in individuals and enacted in social life. For example, Rosemarie Garland-Thomson has written at length about the intersection of the disability studies tradition with other "identity studies," particularly with feminist scholarship, suggesting a direction for the field that is especially fruitful for an STS-based study of an illness community. Her vision of disability studies draws particular attention to the ways in which bodies and the categories used to describe them are both materially and ideologically shaped by social categories that are themselves historically changeable (Garland-Thomson 2002, 2005). There is natural affinity between STS's traditional constructionist approach to scientific knowledge, systems of classification, and technological objects (Pinch and Bijker 1984; Kline and Pinch 1996; MacKenzie 1999) – including how those are applied to and used to regulate groups of people (Hacking 1986) – and the social model of disability. As biomedicine and illness communities become increasingly prominent topics of study in STS, disability studies has much to contribute to the conversation. Several scholars have already taken up this line of study, including STS-oriented anthropologists Faye Ginsberg and Rayna Rapp in their study of how "disability worlds" are inflected by reproductive technologies (Rapp 1999, Rapp and Ginsberg 2012, Ginsberg and Rapp 2013) and media studies scholar Mara Mills'

(2011) work on how hearing disability was to some extent co-constructed with the development of telephonic communication technologies.

While not every food allergy advocate I spoke with explicitly invoked “disability” as a framework for thinking about food allergy management, the claims made on their fellow citizens clearly resonated with the frameworks developed by disability scholars and activists. At least one writer from the food allergy community has taken up promotion of the idea that food allergies falls into the category of “invisible disability”[7] as her *cause célèbre* (Trimner 2013), and the term has come up in numerous conference panels, interviews, and casual conversations with leading experts in the community during my research. Moreover, many adults and children with food allergies in the US seek and receive accommodations under disability rights legislation, making the connection practical as well as theoretical. In this chapter, I will explore these connections, drawing on understandings of patient activism and disability from disability studies, STS, and anthropology of medicine as a lens for interpreting stock epinephrine advocacy in the US.

This chapter brings together two types of evidence in making this case: the still-in-formation public archive documenting the stock epinephrine legislative process (including news coverage, press releases, and social media posts) and open-ended interviews with mothers of food allergic kids who were active advocates for these bills in their home states. The point of these activities, as this chapter will show, is to expand the pool of people who are responsible for preventing harm and death from food allergies through legislative governance of caretaking

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[7] The term “invisible disability” is difficult to trace to a precise moment in disability studies and activism, though it is certainly more common in the scholarly literature since 2000 than before. N. Ann Davis (2005) summarizes the politics of the category well, emphasizing that the visibility of a (perceived) impairment is not necessarily equivalent to its impact upon an individual’s life. Furthermore, she argues, “the very supposition that we can distinguish between bodily or organic causes of disabled persons’ suffering, stress, and disadvantage, and the broader social conditions that shape the experiences of suffering and disadvantage—or even apportion the weight of their respective contributions—is questionable, both as theory and as policy” (p. 155).

practices. In doing so, advocates are redefining food allergies as a disability that can be made less disabling through appropriate social action, rather than a disabling disease that is solely the individual’s problem to deal with. A close examination of a handful of “moral laboratories” (Mattingly 2014b) in which these resources are mobilized will illuminate the ideas about living a “good life” as part of a responsible community that underwrite the activities of the food allergy community.

### Food Allergy in Schools: From Disability Law to Stock Epinephrine

Stock epinephrine bills are but the latest in a decades-long series of legal and legislative innovations that parents use to ensure the safety of children with food allergies in schools. Beginning in the mid-1990s, the pioneering mothers who connected with one another through support groups and nascent national food allergy advocacy groups began learning and teaching each other how to use disability legislation to seek accommodations for their children. The most prominent advocacy organization in the early days was the Food Allergy and Anaphylaxis Network (FAAN), which merged with the research-focused Food Allergy Initiative (FAI) organization in 2012 to become Food Allergy Research and Education (FARE), now the leading food allergy awareness and advocacy non-profit. Without any clear state or federal guidance, requesting and winning accommodations proceeded family-by-family and school-by-school. These pioneers became “expert parents,” analogous to the “expert patients” Steven Epstein (1996) describes as the key movers and shakers in AIDS activism in the 1980s and 1990s. Their expertise was shaped through experience, and through teaching themselves the relevant aspects of biomedical research, as well as legislation, state and district policies, and procedures.

The use of disability legislation is one clue about how parents of food allergic kids and other food allergy advocates are reframing the cultural and legal meaning of food allergies. Food allergy is a diagnosis handed down from a physician, but biomedical interventions do little to prevent severe allergic reactions. To stay healthy and safe, individuals must make changes to their eating, cleaning, and socializing habits. As noted in the previous chapter, the extent of such lifestyle changes can be great, preventing many people with food allergies from eating out or attending family meals, and subsequently leading to feelings of social isolation. With the promise of biomedical cures delayed, pending the outcomes of large clinical trials of new therapies, many actors in the food allergy community continue to focus their attention to ensuring safety in the present for people with food allergies. Living with food allergies bears little resemblance having a “disease” caused by a pathogen which will pass after a period of time. Food allergy persists indefinitely, and like other chronic diseases, it is increasingly eligible for legal consideration under disability statutes.

Many parents today follow in the footsteps of these early advocacy groups, relying on two pieces of disability legislation, Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) (US Department of Justice 2014), to press for accommodations for food allergic children in public schools. The two largest food allergy advocacy organizations (FARE and Kids with Food Allergies (KFA), a division of the Asthma and Allergy Foundation of America (AAFA)) now provide guides on their websites, archived recordings of webinars, and regular conference sessions on this issue. In 2013, the Centers for Disease Control and Prevention (CDC) picked up on this momentum to publish a non-binding set of guidelines outlining the best practices for US schools to follow to manage and accommodate food allergies among children (Centers for Disease Control and Prevention, 2013). Several key pioneers from the food allergy advocacy community – including physicians, advocacy staff, and mother-activists – were named to the CDC panel and actively co-authored the final document, cementing their status as lay experts capable of participating in the formation of expert knowledge concerning food allergies.

Despite these developments, enough uncertainty remains that parents are often fearful to send allergic children to school. One reason is that the burden falls upon the parents to demonstrate that their child’s food allergy meets the federal definition of a person with a disability: as defined by the Americans with Disabilities Act of 1990, an individual with “a physical or mental impairment that substantially limits one or more major life activities of such individual” (US Department of Justice, 2014). In educational settings, public and some private schools are expected to provide accommodations such that children have access to a “free and appropriate public education” (FAPE). There is, however, no universal pathway for demonstrating this and subsequently implementing accommodations for food allergic children in schools. Depending on the school, the severity of the allergy, and the accommodations desired, there are two separate legal frameworks that protect such children: 504 plans and ADA law. The ADA sets the legal standard for providing disability accommodations in public and non-religious private schools. While public schools must do everything necessary to provide accommodations, private schools do not have to take on an “undue burden” to provide accommodations. The ADA provides grounds for legal action against most entities (educational and otherwise) when appropriate measures are not taken. Section 504, which only covers public schools and private schools that receive federal funding, requires schools to do more to identify, appropriately place, and accommodate students with disabilities (though there is some debate about the import of the “reasonableness” of the requested accommodations) (Section 504, Rehabilitation Act of 1973). Section 504 is more practically useful than the ADA, as it outlines the procedures for designing and enforcing a 504 plan, a legally binding document that lays out the accommodations needed by a child with disabilities. A second kind of document, an Individualized Health Care Plan (IHCP) can also be used to describe a child's accommodations, but it is not legally binding (Francoeur 2014).

Within the food allergy community, there is generally an understanding that food allergies "count" as a disability because of the ongoing social and physical effects of the condition.[8] That is, food allergies are a disability because they do not simply run their course; they remain with an individual for their entire lifetime, impairing their ability to participate fully in social life. Moreover, disability status is the only way that children with food allergies can receive legally enforceable protections from their allergens at school. Disability status is strategic as well as, for some, a usefully descriptive marker of health status and a potential identity. Yet classifying food allergy as a disability is not entirely obvious, in part because a person with a food allergy is only periodically made ill – only when they encounter their allergens.

The solutions commonly offered by school districts are not always seen as optimal compromises of safety and social inclusion. Peanut-free tables in lunchrooms often draw ire from peanut allergy moms, for instance. Peanut-free tables are designated tables in school lunchrooms where children are not allowed to sit if they have lunch items containing peanuts. They are typically guarded against contamination and specially cleaned. Sitting at these tables keeps children safely away from peanuts and allows them to attend school, but it also prevents them from sitting with their friends: safety comes at the cost of *certain* markers of social exclusion and potential stigmatization. Food allergy parents are mindful of these kinds of contradictions that

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[8] Julie Livingston's (2005) work proposes another term that might be considered here: debility. For Livingston, eschewing the heavily coded word "disability" is in part a response to her non-Western, postcolonial context. She seeks a term that does *not* carry with it a Western history of activism and debate that hinges on a presumption of individualistic liberal subjectivity. However, since my actors are situated in the United States and, in fact, embrace the resonance of their work with earlier American identity rights movements (of which disability is one), I want to talk *to* and *within* the language of "disability," rather than outside or beyond it.

come with legal protections, and counter the possible negative social effects of accommodations by privately encouraging their children to see food allergies as a positive aspect of their identity, one that makes them more sensitive and conscientious concerning the needs of others. Most resist using that label for their children beyond the school building walls. However, food allergy parents remain bound to bureaucratic parameters of disability because they change the social environment in a way that fosters a greater (if not optimal) degree of social inclusion than might be possible without it.

In practice, then, accommodations ensured by 504 plans or IEPs may not fully address all of a parent's concerns. They may also be followed incompletely throughout the school day depending on the classroom or teacher in charge at different points in the day. Furthermore, food allergy parents are frequently reminded of the libertarian ethos of many of their allergy-free parental colleagues. Parents of non-allergic children often do not take kindly to being told they cannot send their children to school with a peanut butter sandwich or can only send in wheat-free cupcakes for a classroom party. Other parents and visitors to the school forget to comply with such rules, don't know how to do so, or, occasionally, undermine them by intentionally sending or bringing forbidden foods into schools and classrooms.

Internet comments on a regular Huffington Post parenting series about food allergies, to which several parents contribute, reinforce the stories of resistance to food allergy accommodations told to me by food allergy parents. One article, "No Sandwich is More Important than a Child's Life" by Heather Spohr (2015), received over 2700 comments in under four months, many of which used sarcasm and ad hominem comments to accuse parents of food allergic kids of being over-protective and finicky. One commenter's remarks in particular bristled at the idea that some parents could "dictate" the choices of others:

> You could have chosen to home schoool [sic] your daughter or done a million other things but you choose to go to a school that did not have a strict policy forbidding peanut butter ... that was your choice. Now you are affecting everyone elses [sic] choice and belive [sic] the life of your daughter is more important than their choices… Your "holier than thou" mantality [sic] as just as wrong as "I can do what I want" mentality [sic]. There is a middle ground but instead of find [sic] that middle ground you want to dictate to others what is right and wrong.

Such commentary makes food allergy parents nervous that other parents will disregard accommodation involving restrictions on foods allowed in schools or classrooms. If parents of non-allergic children view access to education and dietary restrictions as choices equivalent to those of food allergic people avoiding allergenic foods, they worry, what is to stop them from making the choice to send prohibited, allergy-triggering foods to school despite warnings against it? Protections nominally ensured by disability legislation remain both unacceptably difficult to secure and too easy to undermine in the eyes of many food allergy parents.

A new kind of legally enforceable protection for people with food allergies is the provision of “stock” epinephrine autoinjectors in public spaces. As discussed in chapter three, epinephrine auto-injectors are objects that practically mitigate the risk to life posed by serious allergic reactions as well as symbols of the food allergic person’s “diseased” status. As such, they symbolize both safety and fear for people in the food allergy community. Unlike other potentially life-saving technologies available in public spaces, like cardiac defibrillators, epinephrine auto-injectors are devices that contain an active, prescription-only pharmaceutical medication. Therefore, their use is ordinarily restricted to those individuals who have been prescribed the device by their physician. “Stock” epinephrine, by contrast, is prescribed by a physician with the intention that the device will be stored in a public space and used on anyone who happens to need it. The device is, in effect, “prescribed” to the particular entity (organization or company) that controls a public space or place of business. In the food allergy community, laws governing epinephrine in schools are typically referred to as “school epinephrine laws" and laws governing the drug in any and all other kinds of public spaces are referred to as "entity laws." So far, entity laws – many of which were just being drafted or presented to legislative committees in 2015 – have targeted public spaces that advocates associate with "normal" middle class family life, like churches, summer camps, and restaurants. In most states (Fig. 1), stock epinephrine laws are written so that stock epinephrine will be *allowed* to be stored in public places, but not required.

The most important feature of these laws is to remove legal liability from those who administer the medication and the physicians who prescribe it. Prescribers, school nurses, and teachers have voiced objections through unions and professional representatives to providing and using epinephrine auto-injectors if they face the possibility of being sued in the event of complications. In the litigious United States, this scheme – portrayed as life-saving by advocates – only works if no one can be blamed for a bad outcome. As Jain (2006) points out, the impulse to pin bad outcomes from consumer products on a particular individual is a signature function of product liability law in the United States. Or, as she acerbically puts it, "to consume is American. To sue is American" (Jain 2006, 1). Like Douglas's (1990) "forensic" theory of risk or Laidlaw's (2010) rereading of the collapsing granary in Evans-Pritchard's classic ethnographic account of the Azande, Jain points to a desire to assign blame for misfortune that appears to be broadly shared in human societies across place and time. From this perspective, stock epinephrine laws short circuit the search for blame and preempt anticipated tort suits in order to give actors in future emergency situation the legal leeway to act in the best interest of the food allergic patient.

Another dimension of school stock epinephrine bills is the way that they add another layer of preparedness to the mechanisms already in place to safeguard children with food allergies at school. The basic idea behind stock epinephrine bills is to make epinephrine available in specified public settings, like schools, where individuals may experience unexpected anaphylactic reactions requiring immediate treatment. This logic mirrors the thinking behind emergency defibrillators and first aid kits: provide easy-to-use medical tools in public places so that onlookers can, if necessary, provide basic medical care to someone in need in the event of an accident or emergency.[9] In the event that the worst comes to pass – that a person suddenly becomes so ill that they are close to death – such tools promise a kind of insurance against life-threatening danger. They anticipate a course of action in the mode that Ben Anderson, following Brian Massumi, describes as “precaution,” “a preventative logic.” Precaution, in his view, is characterized by two features: an “object [that] could develop a catastrophic outcome if the precautionary act was not to take place” and a need to “act before the identified threat reaches a point of irreversibility" (Anderson 2010, 13). The provision of easy-to-use medical tools in public spaces, like AEDs, first aid kits, and stock epinephrine, are prime examples of how public health policy follows precautionary logics. These tools all intervene in injury and illness before the harm becomes “irreversible” – before cardiac muscle is damaged, before infection sets in, before oxygen deprivation due to airway obstruction as a result of anaphylaxis damages a child’s brain.

Schools have emerged as the first major target of stock epinephrine laws for a number of reasons. For one, mother-activists were already on the scene, learning what disability legislation could and could not provide through hands-on work with local school districts across the U.S. Advocacy organizations fostered the organized collection, sharing, and communication of this

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[9] Timmermans’ (1999) study of the history and modern use of CPR offers an interesting comparison. His historical research suggests that CPR does not save many lives because most people die anyway. While there is not good comparative quantitative evidence for outcomes of anaphylaxis with vs. without epinephrine, judging by the number of conversations I’ve had about patients not using epinephrine when they “ought” to and coming through just fine, epinephrine probably doesn’t save as many lives as purported because many people would likely survive without it. With both CPR and epinephrine, time is also said to be of the essence, with quicker administration preventing adverse outcomes due to oxygen deprivation and circulatory collapse.

knowledge. By the late 2000s, there were many mothers who knew what *couldn't* be achieved in schools under existing legal frameworks and who were interested in changing the law to do more. In addition, savvy activist parents recognize that framing stock epinephrine bills as a way to protect children is the most politically expedient way to achieve legislative success. Advocates reason that politicians can hardly refuse to support a bill that potentially saves children from death. Starting with school epinephrine bills is strategic, since most advocates and activists anticipate that school epinephrine laws are just a first step to more wide-ranging entity epinephrine legislation.

There is an irony to all of this in the context of the stock epinephrine advocacy movement: advocates rely on moralistic entreaties to protect innocent children in order to pass laws that defer moral blame. In order to act responsibly, non-parental caretakers of allergic children must first have a legal framework so that they will not be assigned responsibility if something goes wrong. The law functions as an important moral arbiter in this context, providing a legal limit to the forensic tendencies of parents, professional oversight frameworks, and others who may be tempted to assign blame for a bad outcome following the administration of epinephrine in a moment of crisis.

Stock epinephrine laws, the latest way to ensure the inclusion of children with disabilities in "normal," everyday life, do double duty: they offer a new way to reshape the social environment to safeguard the lives of people with food allergies and they enable bystanders to intervene without the potential of legal repercussions in the event of a serious allergic reaction. In the future they imagine, allergic individuals – especially children – can be struck with anaphylaxis at any moment. The precise timing is indeterminate. So too is the precise identity of the potential victim. Even for children with some prior evidence of food allergies, there is imprecision about *which* food or *which particular* reaction will provoke potentially life-threatening multi-system anaphylaxis. Preparing the social environment for these possible moments of disaster is a way to not only ensure the integration of people with food allergies into ordinary life – a good goal by the measure of proponents of the social model of disability – but also to materially enact certain visions of a risky future by placing epinephrine auto-injectors in schools.

Activists who are pushing for stock epinephrine thus simultaneously leverage a disability frame that lays blame for social exclusion at the feet of society at large, to be remedied through a shift in cultural attitudes toward physical difference (Shakespeare 1996, Barnes 2012), *and* a disaster narrative (instantiated in legislation as well as in the "death talk" used in awareness rhetoric introduced in chapter three) in which incipient disaster lurks ubiquitously, to be controlled through planning and preparedness at both institutional and individual levels (Lakoff 2008; Adams et al. 2009; Anderson 2010). While the disability frame has been part of managing food allergies for school children under other legal frameworks, such as disability law, the disaster preparedness angle, including, but not limited to, "death talk," offers a new spin on efforts to accommodate people with disabilities in public life. As the next section will show, the disaster narrative that justifies stock epinephrine legislation has been presented in other types of organized food allergy advocacy and awareness campaigns in the US. Indeed, it often dominates activists' efforts to publicize and pass these laws. Ultimately, activists are seeking ways to ensure that children with disabilities have access to what they see as "the good life" (Mattingly 2014b) – a "normal" life where social inclusion does not put children with food allergies at risk of death from anaphylaxis.

## Advocacy Approaches to Stock Epinephrine Legislation

Not-for-profit food allergy organizations have led the way in positioning stock epinephrine bills as the way to provide a necessary framework for allowing people with food allergies to fully participate in American society. This is one part of their project to position epinephrine as a life-saving substance and the epinephrine auto-injector as a necessary technology for responsible food allergic people and their caregivers, themes introduced in chapter 3. Their organizations help to standardize and communicate the narrative of the moral life of epinephrine. Tax-exempt, 501c3 not-for-profit organizations of various sizes are instrumental players in this advocacy field. A handful have risen to prominence, building credibility through their origins as patient- and parent-led organizations, as well as through the reputations of the physician-researchers who sit on their advisory boards. In recent years, these organizations have bolstered their "lay expertise" (Epstein 1996) with professional staff with experience at other non-profits or healthcare industry players, and with advisory boards made up of leading researchers in allergy and immunology. The two leading organizations in the field – Kids with Food Allergies (KFA), a division of the Asthma and Allergy Foundation of America (AAFA), and Food Allergy Research and Education (FARE) – will be featured in the coming pages.

Other STS scholars have identified the importance of organized patient activism and advocacy for ensuring access to medical care and legal protections. Such scholarship has often emphasized what activists have to do to gain recognition as credible political representatives for patients, and to gain access to medical research and treatment (K. Fortun 2001; Allen 2003; Murphy 2006; Epstein 1996; Callon and Rabeharisoa 2003). The *realpolitik* behind strategic alliances of mothers, professional advocates, and scientific authorities that give shape to the stock epinephrine movement are less my focus in this section than how they position food allergies as a cultural phenomenon and public health crisis through their advocacy efforts. This positioning helps, in turn, to regulate the moral reasoning characteristic of actors in the food allergy world and their potential, or hoped for, allies. Stock epinephrine legislation offers a way to define, intervene upon, and ultimately control the potential of food allergies to harm allergic individuals. The indeterminate terrain of ubiquitous risk that mothers and adult patients described encountering upon a food allergy diagnosis in previous chapters is replaced by a bounded problem – anaphylaxis in a public place – that can be countered by using a prescriptively defined solution – a stock epinephrine auto-injector.

To date, these campaigns – focused as they have been upon school stock epinephrine legislation – have also narrowed the *population* defined to be at risk and specified *where* they face that risk, namely, children at school. Largely absent from the risk calculation so far are adults with food allergies and public environments other than schools. Sites like churches, summer camps, and restaurants are held in reserve as the next step for stock epinephrine legislation, once the battle to cover schools is won. This planned progression is strategic, beginning with those conversions thought to have the strongest moral footing, and therefore the highest likelihood of success (stock epinephrine in schools), before turning to contexts with more complicated and powerful moral and political forces, like stock epinephrine for lightly regulated industries (summer camps, churches) and politically powerful constituencies (restaurants and the hospitality industry).

The campaign for stock epinephrine in schools relies on a combination of statistics, fear, and entreaties to protect vulnerable children. For example, in its justification for making stock epinephrine in schools a priority for advocacy work, FARE’s web page about epinephrine in schools cites the statistic that “approximately 20-25 percent of epinephrine administrations in the school setting involv[e] students or staffers whose allergy was unknown at the time of the event.”

Stock epinephrine is positioned as helpful for those children who do not have a known diagnosis. It is potentially a significant public health intervention considering that most children in the US attend public school for half of more of their waking hours. Stocking “undesignated” stock epinephrine auto-injectors is described as a way to “help save the lives of those who experience an anaphylactic reaction and don’t have a prescribed epinephrine auto-injector” (FARE 2015b). Texts that assert the life-preserving properties of epinephrine are the corollary to the death talk that circulates in the food allergy world. As a preventative of anaphylaxis deaths caused by food allergy, they offer hope of safety for people with severe food allergies, but a hope that is closely tied to fears of illness and death. Epinephrine auto-injectors retain their morally charged status in conversations about stock epinephrine legislation.

The Asthma and Allergy Foundation of America (AAFA) is another advocacy organization active in the food allergy domain. Through its Kids with Food Allergies (KFA) division, it puts some of its considerable weight behind food allergy legislative advocacy. In 2013, AAFA released a statement regarding stock epinephrine bills that featured much stronger language about the life-saving potential of epinephrine:

> Anaphylaxis is a serious medical condition, which can be life-threatening if rapidly developing symptoms are not treated promptly… With prompt injection, epinephrine is nearly always effective in the treatment of anaphylaxis. Delay increases the risk of poor outcomes and even fatalities… The facts are simple: when available, epinephrine auto-injectors save lives. (Asthma and Allergy Foundation of America, 2013)

The press release continues, emphasizing the necessity for schools to protect the children in their care:

> Children spend a sizeable amount of their time in school, whether for daily instruction or recreational activities. Therefore, schools must be prepared to address the safety of their students. (Ibid.)

The document also appeals to fear by recounting a death talk story about a Virginia first-grader who died from anaphylaxis during school recess in 2012. Within the food allergy community, this case is seen as a watershed moment for stock epinephrine legislation. It triggered a parent-led movement to pass school stock epinephrine legislation in Virginia and provided a template and parent experts for groups in other states to draw on when promoting their own bills. In the KFA press release, the incident is used to underscore the importance of stock epinephrine legislation as a way to protect children.

> [The first grader] was rushed to the school nurse and 911 was called. By the time the ambulance arrived, she had gone into cardiac arrest. She died a short time later at a nearby hospital. Her tragic passing instilled a sense of urgency in Virginia to protect school children and Virginia passed a law requiring schools to maintain a supply of epinephrine auto-injectors. (Ibid.)

These sorts of press releases and other public awareness information from allergy advocacy organizations position epinephrine availability as a moral imperative to save children. When these messages originate with national advocacy organizations with millions of dollars of annual revenue and professional lobbying staff, they benefit from the visibility of their association with national not-for-profits. Messages are forwarded to and from parent-led support group listservs, food allergy discussion groups on Facebook, and between official non-profits and their followers on social media platforms like Twitter and Pinterest. As they are amplified through these channels, they help to set the stage for legislative action at the state and federal levels. Perhaps most importantly, because of their reach and the credibility of these organizations, these messages play a role in standardizing the messaging and language that are ultimately used in direct legislative advocacy for stock epinephrine.

Individuals from parent advocacy groups allied with major non-profits – particularly FARE – also spoke out in favor of stock epinephrine bills on online platforms such as blogs and Twitter feeds. Leading up to a legislative vote for a stock epinephrine bill in California in May 2014, for example, food allergy advocates on Twitter posted a stream of messages urging followers to vote in favor of the bill. User @CaAdvocatesFA was especially prolific in the days leading up to the vote, tweeting at politicians and regional news outlets, and posting both original appeals to action and retweets of other users' messages. On May 20th, @CaAdvocatesFA posted a series of messages about the importance of stock epinephrine, one of which included the entreaty, "A child's life is worth the cost of stock epi." In another original message, they stated, "We can either save the next child with stock epi or wish we had." Accompanying this message was an image that was subsequently widely shared. The image was bounded by a simple black rectangle, and the words were written out in sans-serif font, imitating the style of some recent internet memes. In the bottom right corner of the image, a cartoonish line drawing of a person, presumably a child, stood with open mouth and a red heart set against the baby blue of its shirt. The message from this user (and many others) was clear: requiring epinephrine in schools is a life-saving move. To think otherwise is to condemn children to death, this Twitter user suggests.

*Figure 6. "We can either save the next child with stock epinephrine or wish we had." Tweeted by @CAAdvocatesFA May 20, 2014.*

Several months after following the progress of the California stock epinephrine bill from a virtual vantage point, I spoke to a mother-advocate, who I will call Cindy, who was one of the leaders of the social media push and legislative advocacy campaign in the state. Our conversation provided me with a behind-the-scenes account of the advocacy work that went into passing the California law. It also clarified the reasons for her personal commitment to stock epinephrine bills, echoing much of what I had heard from other parents and advocates in informal conversations online and during conferences throughout the previous year. Her narrative of the process highlighted the political opposition the legislation faced in her state. That opposition largely came from the California Teachers Association (CTA), the state's large and politically powerful teacher's union. It also illustrated how her own position as a middle-class woman with a strong educational background and family ties to the media and political establishments facilitated her work. Not just any mother could have accomplished what she did: both her dogged dedication, enabled by her family's class position and her ability to leave the workforce to raise her food allergic son, and her social position were crucial to her ability to affect policymaking.

From the start, this advocate's involvement was shaped by family ties. The seed was planted in the summer of 2013, while she was working with a fellow food allergy parent whose son had died due to an allergic reaction. They were organizing a food allergy fundraising walk with FARE. His personal tragedy motivated him to work on the national bill encouraging states to pass stock epinephrine legislation, the School Access to Emergency Epinephrine Act of 2013. Now he was itching to update the legal framework in California; though it had been in place for a decade, it only allowed voluntary stock epinephrine use. Few schools had invested in the training and supplies necessary to make stock epinephrine availability optimally effective under the voluntary framework. His belief, and later Cindy's, was that only a mandatory state law – one that compelled entities like schools to carry stock epinephrine – would be effective in broadening access to epinephrine.

Her interest was piqued by their encounter, and subsequent events facilitated moving ahead with the idea. That fall, state senator Bob Huff visited Cindy's son's elementary school class to talk about the legislative process. The senator encouraged the students to bring "really, really good ideas" for new legislation to his office. Cindy's son proposed the idea of a stock epinephrine bill. By November 2013, she had leveraged her personal network to schedule a series of meetings at the senator's office to promote the concept. It turned out that she had worked for the senator's father at his family business when she was a teenager, giving her expedited access to the senator. Senator Huff decided to take up their cause, ultimately sponsoring SB 1266 with another legislator from the opposing party who had been considering introducing a similar bill. The bill was introduced late in February 2014.

With bipartisan support and initial enthusiasm from her Senator Huff, Cindy anticipated that the process would go smoothly until the bill was passed. She took on the role of handling media, public relations, and social media. Her partner for this mission, another California-based mother-advocate, liaised with the legislative sponsors' offices and FARE. FARE assisted by encouraging their listserv subscribers to show California legislators their support for the bill through letter writing and messages on social media. Together, they positioned the process to unfold in public view. Soon, however, Cindy's team began hearing rumors of resistance from the California Teachers Association (CTA). Their complaints with the bill focused on teachers' lack of training for administering a powerful emergency medication, concerns that there were too few school nurses to train teachers and staff, and worry that teachers could be held liable in the event of a child's injury or death.

Frustrated by resistance from the CTA and the lack of interest within the state (even, in her view, within the state food allergy community), Cindy contacted a reporter friend at a local news station. The reporter broke the story in their high-density part of the state. According to Cindy, that made all the difference: "The story broke. It was out in the open that the CTA was opposed. [That was when] the grassroots movement really took off." Exposing the apparent moral contradiction in the CTA's position – that teachers, children's primary caretakers during the day, were unwilling to support a measure designed to protect children's health – was a important factor in garnering support for the measure. Following the story, advocacy support – in the form of letters, phone calls, and social media entreaties to state legislators – became more consistent and widespread among the California public. Her own efforts often focused on promoting social responsibility toward children specifically, targeting legislators whose platforms focused on protecting socially vulnerable low-income children or children of color.

However, rather than stay on the defensive against such a powerful political player as the CTA, they also designed what Cindy called "a classic example of a compromise" to assuage teachers' fears about liability. It was true, after all, that some schools did not have an assigned nurse, or that a single school nurse was often in charge of overseeing an entire district of hundreds to thousands of students and multiple different locations. Nurses would be stretched too thin in trying to train teachers to use stock epinephrine, as their normal responsibilities included training teachers and staff in the administration of medications. The bill would add responsibilities for teachers and school nurses that would go above and beyond their contract, or add duties without taking away others or adding compensation. To accommodate schools where training would be a challenge, they eliminated the mandatory provision. Instead, schools with a district or school nurse would be expected to carry stock epinephrine, and that nurse would be expected to carry out training with teachers and staff and maintain the epinephrine auto-injectors. In schools without a nurse, another staff member could implement stock epinephrine by volunteering to take on the responsibility of training and maintenance. With these changes written into the bill, California's governor, Jerry Brown, signed it into law on September 15, 2014.

In Cindy's eyes, SB 1266 is only the first step toward providing stock epinephrine in public spaces in California. When we spoke about stock epinephrine in May 2015, a new bill was in the works to expand stock epinephrine bills beyond schools to a wider array of public spaces and businesses. Cindy was not directly involved in this new effort, but watched from the sidelines. Spearheading the push for the new "entity bill" is Mylan, the maker of the EpiPen, currently the leading epinephrine auto-injector. Mylan's involvement in stock epinephrine legislation has been uneven and at times controversial within the food allergy community (the section that follows will explore their involvement with mother-led stock epinephrine legislative advocacy in other states). In this case, Cindy sees both opportunity and troubled waters ahead. Better reporting of incidents where children die from allergic reactions could alert legislators and the public to the political and public health expediency of stock epinephrine. However, she believes restaurant industry organizations will pose a lot of resistance. Moreover, since an entity bill would be much less exclusively focused on protecting *children*, she reasons that the moral imperative to protect food allergic people would be less compelling to the public. With school epinephrine, she explained, it is understood that children will be the prime beneficiaries. It's harder to say “just let the kid die” than to fail to put in place additional protections for adults who are generally expected to be more skilled at researching and avoiding their allergens.

Cindy’s experience advocating for SB 1266 in California in 2013 and 2014 highlights many of the moral dynamics of food allergy advocacy. Tellingly, she gets involved in the effort based on her direct experience of living with a food allergic child and based on her acquaintance with a parent whose child actually died from an allergic reaction. This sort of immediacy is common among people in the food allergy community who actively promote disease awareness and legislative change. An allergic child often (although not always) launches a middle-class mother into the world of fundraising walks, support group leadership, social media campaigns, and working closely with local, state, or national lawmakers. A beloved allergic niece, nephew, or grandchild can draw more distant relatives into the fray. Food allergy-related business owners, like John in the previous chapter, may use company funds and their visibility as corporate leaders to push for these bills as well. Allergic adults also get involved, often by proxy via an allergy-related food manufacturing company or counseling practice. Legislative advocacy for most in the food allergy community is an extension of a personal experience with the condition – an extension of the responsibility to care for one’s allergic self or loved ones to ensuring safety for unknown allergic individuals in the community.

The special moral status of children is significant here. As Cindy suggested in our interview, stock epinephrine in schools laws are *just easier* than broader entity legislation because they are understood to specifically and exclusively protect the lives of children. Advocates like Cindy assume that broader entity laws protecting restaurant patrons are not likely to carry the same moral weight. While no legislator could vote against a bill pitched as a tool to save children’s lives and expect to escape future attacks from parents and education industry lobbies, ignoring a measure that allows allergic adults to more safely dine out – an activity that not only appears to be a choice but which also suggests a certain upper-middle-class concern with the freedom to consume luxury goods – carries little political risk. The story of stock epinephrine advocacy brings this differential in responsibility owed to children versus adults into sharp relief. In short, some lives matter more than others, a fact which food allergy advocates – mostly mothers themselves – leverage to political advantage.

Advocacy rhetoric reinforces the status of epinephrine auto-injectors as a technology with the ultimate moral significance: arbiters of life and death. This association of auto-injectors with life-and-death matters is common throughout food allergy awareness and advocacy campaigns, as well as in everyday life in a family with food allergies. In the context of stock epinephrine advocacy, this association is meant to encourage others – most commonly school and community officials and state politicians – to appreciate the seriousness of food allergies in order to persuade them to support these bills. As school stock epinephrine legislation becomes more common, epinephrine is more specifically being linked to saving the lives *of children*, often through the efforts of mothers. This is a strategic decision made by legislators and both professional and parent legislative advocates in the United States. The next section will show how these seemingly pure motivations attract industry allies to the cause, at times creating friction within the ranks of food allergy activists and suggesting similarities between the food allergy advocacy movement and other health activism causes in recent history.

### Mothers as Advocates: Industry Alliances and Doubts

Mothers have been key to successfully passing the initial round of stock epinephrine legislation bills focused on providing access to epinephrine in schools. This section picks up where the last one left off, with analysis of another narrative of the stock epinephrine legislative process told to me by a different prominent food allergy mother-activist. The network of mother-advocates involved in stock epinephrine advocacy consists of middle-class women with various ethnic and cultural backgrounds and modes of professional expertise who are motivated by the moral purpose of protecting their children and others like them. They present their case to legislators and to the public with a self-consciously polite and professional façade. Doing so brings women into the fray of political advocacy, but shows them engaging on the terms set by others, in this case, the terms set by lawmakers and big pharmaceutical companies, and within a traditional framework of the role and comportment of middle-class women. This mother-advocate's story underscores how they perform the roles of feminine caretakers, the moral guardians of the next generation, appropriately occupying their time fighting for the good of their children.

Before jumping into her story, it must be noted that this is far from the first time women (including mothers) have been instrumental in raising awareness about access to medical care. The history of women's health in the 20th century is filled with instances where the consciousness-raising practices developed by the women's rights and women's health movements were instrumental in aggregating knowledge about female bodies and using that expertise as a platform for scientific and political activism (Lerner 2002; Murphy 2004, 2006, 2012; Jain 2013). Sharing experiences in the context of consciousness-raising groups – the same institutions (though now called "support groups") from which the large-scale food allergy advocacy groups were born – offered a way to connect as women and as sufferers/patients. By "raising consciousness" in this way in multiple, loosely connected groups over time, these groups laid claim to an "objective" understanding of women's health and experience that was not "scientific" per se but grounded in the embodied experience of illness and society, and often discussed and recorded systematically. Michelle Murphy's work additionally highlights how the intersection of gender with race and class shaped whose voices could be included in these movements in the 1960s and 1970s, with women who were white and middle- to upper-middle-class typically speaking the loudest. These patterns of sociality persist in the food allergy advocacy community today.

Consonant with the shift from second-wave to third-wave feminism since the 1970s, and given the particulars of the food allergy advocacy community, food allergy advocacy is largely led by *mothers* advocating *politely* on behalf of their children – not *women* agitating *militantly* on behalf of themselves and their embodied experience. Women's studies scholar (and food allergy mom) Heather Hewett refers to this change in the terrain of middle-class American women's activism as a nascent "mother's movement" (Hewett 2006). For many of the mothers involved in promoting stock epinephrine laws, getting involved with legislative advocacy offers a sense of purpose and an opportunity to collaborate with other food allergy mothers throughout the United States. As illustrated through the narratives of other food allergy parents in chapter four, many of these women put their careers on hold, either temporarily or permanently, to make caring for their food allergic children their full-time jobs. The women who have been instrumental as support group leaders or legislative activists are mostly white and overwhelmingly middle- to upper-middle-class. Getting involved in the legislative process is an opportunity for stay-at-home moms to use rusty professional skills – legal, graphic design, medical, leadership – to build new, purposeful, morally united networks. It is a socially and morally appropriate exercise of professional skill for the mothering class.

One mother, whom I will call Denise, is widely credited as a national leader in the push for stock epinephrine legislation. Though we met late in my dissertation research, we have since stayed in close contact, and have spoken by phone and in person about her current and past advocacy work numerous times. In her small western state, a stock epinephrine bill had been introduced and passed in just a year and a half – a feat that is particularly remarkable given that this state's legislators only convene in session every other year. Denise had been active in the food allergy community since her now-16 year old son was about two years old. He and her 11-year-old daughter both developed allergies in infancy, including nut, flaxseed, and sesame allergies. She became a recognized voice in the food allergy community in part due to her blog, which she started in 2011. Through this platform, she offered advice to other parents of food allergic kids, ranging from tips on dealing with school policies to recipes for how to bake delicious nut-free desserts. By the time stock epinephrine legislation became a cause célèbre in the food allergy community, she had been wrangling with school district food policies for over a decade. She got involved directly in stock epinephrine advocacy after the Virginia bill was under way and used some of the tactics that others had used before. More than anyone I have spoken to, she has become an important hub for food allergy legislative advocacy.

Denise got involved in stock epinephrine legislation in April 2012 via her then-preteen son's interest in the issue. He attended a national advocacy organization's "Kid's Congress" advocacy day in Washington, DC several years ago where he and Denise met US Senator Harry Reid. When Denise asked Senator Reid how she could help advocate for stock epinephrine in schools legislation, he recommended that she look into advocating for state-level bills, as a national bill would be impractical. After the trip, she did some research on state legislators in her home state who might be interested in sponsoring such a bill. To pitch the idea, she got in touch with a legislator who was known for his work promoting education policy and who sat on a number of committees relevant to such a bill (including judiciary, education, and health and human services committees). The legislator was supportive, but there was still plenty of work for

Denise to do to support the effort – much more than she originally anticipated. She quickly set about enlisting allies – including fellow parents and a lobbyist friend in the state who donated his time to advising Denise on the legislative process – and weighing in on early drafts of the bill.

The tone all changed that summer when an unexpected player entered the scene: Mylan, the maker of the EpiPen brand of epinephrine auto-injector. Mylan's logo and sales reps are common sights at food allergy events. As noted in Chapter Three on "The Moral Life of Epineprhine," many in the food allergy community view Mylan ambivalently due to the company's aggressive pricing strategy for the EpiPen. They have underwritten nearly every food allergy event I've attended, ranging from national physician conferences drawing thousands of attendees, to national advocacy events with hundreds of support group leaders, researchers, and interested parents, and to a small seminar for school nurses held in a school auditorium. Mylan has much to gain from joining the stock epinephrine scrum: not only the possibility of thousands or millions of EpiPens sold to schools and other entities, but also a boost to its image as a company with a sense of social responsibility toward its EpiPen customers. It adds a moral component to the economic strategy of maximizing EpiPen sales. From Denise's point of view, Mylan seemed surprised to find that mothers and legislators in her state were already working on stock epinephrine legislation. Mylan entered the state with plans to put forth a pre-formulated bill and initially viewed parent advocates, according to Denise, as "bonbon-eating moms. … They literally wouldn't look me in the eye. They were pissed! They had a bill, and we were messing it up." In Denise's view, "they were not kind ... they were pretty hostile," despite being welcomed as a powerful ally in the process.

From the start, Mylan's strategy was different from that of Denise and her collaborators. Based on her research, Denise had narrowed the advocacy strategy in the state to require stock epinephrine in K-12 schools. Crafting such a bill required a careful understanding of sometimes idiosyncratic state policies and legislative vocabulary – expertise that Mylan initially lacked. For example, Denise explained that the corporate bill initially specified that “any campus” would have to carry stock epinephrine. In her state, as educators from a state school district informed her group, school buses were considered part of the “campus.” It was anticipated that requiring stock epinephrine on buses would prevent the bill from passing, so that language had to be changed. State nursing statutes also shaped how certain provisions could legally be worded. Mylan’s bill would also have required a wider variety of educational institutions – including pre-schools and universities – to carry stock epinephrine, but state-based work groups determined that including those entities would open the bill up to being killed in committee. By contrast, narrowing the involved groups of stakeholders to schools, school nurses, Mylan, and parent groups, and reaching out to include them in the writing process, helped build consensus as the bill was torn apart and rebuilt before its committee hearing. This proved to be especially important when, on the Sunday prior to the bill’s Wednesday committee hearing date, the bill was rewritten from scratch. Since agreements had already been reached to narrow the field of educational institutions to be covered, the task was doable, if still demanding.

After the bill was rewritten, it landed in committee in February 2013, where mother-advocates (including Denise) took center stage, winning over both legislators and skeptics from Mylan. They relied heavily on feminine charm, effusive expressions of parental concern, and direct testimony from their children, in addition to clear explanations of the technical features of the bill from its legislative sponsor and Denise’s lobbyist ally. All of the parents had been coached ahead of time to stay within time limits, to address lawmakers in the audience using appropriate honorifics, and above all to be both “professional” and “sweet” at all times. Denise explained that in order to counter resistance from the teacher’s union to using epinephrine auto-injectors, she had her own 9-year-old daughter demonstrate the device. The subtext was clear: this tool is so easy even a child can use it. A physician testified on the medical dimensions of epinephrine auto-injectors, and a nurse spoke about her experience with parenting a food allergic child. Other parents from the major city in the state supported the effort as well, speaking about their emotional reactions to reports of children dying from allergic reactions, and bringing death talk into the legislative realm. This testimony was enough to get the bill past committee. It then sailed through both chambers of the state legislature to be signed into law on June 3, 2013. Meanwhile, in Denise’s words, the testimony convinced Mylan that “food allergy parents are a force to be reckoned with – and a good force.” The parents would always be part of the process, so it would be up to Mylan to “earn their keep” as these bills were introduced state by state.

The mother-advocates’ relationship with Mylan throughout this process deserves a moment of further analysis. At the time of this writing, August 2015, Mylan is one of the most important generic drug makers in the world. It recently fended off a takeover attempt by Israeli Teva Pharmaceuticals, an anticipated $40 billion deal that would have created a generics company with 25% of the industry’s worldwide market share (Silverman 2015). Teva instead acquired Allergan, another major generics maker and the maker of Botox, allowing it a “graceful exit” from the much publicized deal (Unmack 2015). Mylan is now mulling over its own takeover options, with its sights set on Irish generics powerhouse Perrigo. In the midst of this corporate wheeling and dealing, Mylan carves out resources to fight alongside mothers in state legislatures. Meanwhile, as discussed in Chapter Three, users were reeling from sticker shock: the out-of-pocket price of epinephrine auto-injectors to patients has risen from approximately $35 in 1986 to over $300 in 2015 (Koons and Langreth 2015; Woodrum 2015a).

Although Mylan representatives were not interviewed in the course of the research for this dissertation, I detect three converging trends in pharmaceutical company governance and marketing motivating their involvement. What I know of their approach comes from reading documents on their website, reviewing EpiPen marketing materials, speaking to their salespeople in casual encounters at conferences and educational events, and speaking to those mother-advocates who had firsthand experience working with their corporate representatives.

First, their involvement with stock epinephrine legislation follows the rise of corporate social responsibility (CSR) programs. This approach offers a new twist on the tactics of traditional "detail men" (Greene 2004) who sold drugs to physicians by building a complex gift economy that inspired product loyalty and promised to keep them on the cutting edge of medical science (Oldani 2004). CSR programs present a friendly "face" to the public, their consumers, and shareholders as a way to anticipate and short-circuit activist critique of the effects of company procedures (Welker 2009, Shever 2010, Dietrich 2013). In the case of a pharmaceutical company like Mylan, critiques often center around differential access to drugs and other health care technologies, including the effects of drug pricing practices. Mylan's publicly available 2015 Corporate Social Responsibility brochure offers a window into their effort to diffuse such concerns: their CSR portfolio highlights everything from low-cost access to AIDS drugs in India to employee health and investment benefits programs to stock epinephrine advocacy. In the "Combating Anaphylaxis" section, they highlight their involvement by stating, "we have spearheaded and supported multiple efforts to help raise anaphylaxis awareness, preparedness and access to treatment" (Mylan 2015, 40). Two pages later, they tout their "EpiPen4Schools" program, which "provides four free EpiPen or EpiPen Jr (epinephrine injection) Auto-Injectors to qualifying U.S. schools along with additional training and educational resources for schools" (ibid., 42). The top half of the page is taken up by a soft-focus (and oddly low-resolution) picture of the Mylan-branded cabinet in which the free devices are intended to be stored.

Their involvement in the stock epinephrine movement thus has two sides: they show that they “care” about their consumers beyond generating sales, but do so through championing legislation that mandates certain entities to purchase their products. One mother-activist channeled a common concern about the company’s long-term strategy when she said, reflecting on this program, “they’re under no obligation … eventually, that [program] stops.” Whether Mylan’s support of the food allergy community is a sincere, long-term commitment to patient wellbeing or a cynical ploy to boost sales remains to be seen.

Second, their sensitivity to patient groups reflects a growing understanding among pharmaceutical companies and pharmaceutical marketers that collaborating with patient groups provides direct access to patient concerns. Patient critiques affected the conduct of clinical trials and eroded the public image of companies involved in AIDS research in the late 1980s and early 1990s (Epstein 1996). The critiques only stopped once these groups were included in clinical trials design and other key decisions. Now, consultation with patient groups is an integral part of pharmaceutical development and marketing. Like the advocates for victims of the Bhopal, India Union Carbide chemical spill that Kim Fortun describes, food allergy advocates become caught up in “double binds” with corporations who have financial interests in their health status. These “fields of force and contradiction” bring together seemingly unnatural allies in temporary and complexly layered ways to achieve political goals on behalf of patients who would otherwise have greater difficulty accessing political power (K. Fortun 2001).

The possibility of accessing patient groups is itself a byproduct of the third trend, a shift toward biosocial, or biosocial-like, social relations (Rabinow 1992). Rabinow defines biosociality as “a circulation network of identity terms and restriction loci, around which and through a truly new type of autoproduction will emerge,” which coalesces around “the new genetics” that encourages patient identification with their genetic risk and disease profiles (241). Food allergies may or may not fit Rabinow’s precise definition: nearly everyone with food allergies first finds out about their own allergies through an actual reaction to the food, rather than through the measurement of a biological marker. Nonetheless, if biosociality is understood as a more general mode of sociality, where shared biological dysfunction, risk, or illness brings patients together, it is an important part of disease experience in the contemporary United States. Its importance, as already noted, has not escaped those companies who make products to treat biomedical disease entities.

Engagement with patient groups large and small has become an integral part of pharmaceutical company practices because of the collected knowledge, experience, and desires that these groups contain. This knowledge and experience is a key source of financial value in the emerging age of biocapital (Rose 2001; Sunder Rajan 2006). A new generation of start-ups, collectively referred to as “health tech” and mostly based in Silicon Valley and its New York City spin off, called “Silicon Alley,” share a business model that takes advantage of the pharmaceutical industry’s thirst for patient information. These new biocapitalist success stories regularly attract tens to hundreds of millions of dollars by promising investors that they will make money at an ill-defined moment in the future by selling aggregated user information to pharmaceutical, food, lifestyle, and marketing companies. It remains unclear how many of these investments, hedged slightly in investor communications using forward-looking statements, will ultimately pan out (M. Fortun 2001). What is clear is that patient experience is now big business. Given these developments, Mylan’s direct involvement in legislative advocacy seems, if anything, to be behind the times, relying as it does on in-person relationships and direct engagement with patient groups instead of an all-seeing algorithm or snappy slide deck.

### Food Allergy as Risk, Food Allergy as Disability

Examining the evolution of legal protections for food allergic children at school, including the role that mothers play in legislative advocacy, draws together several strands of thinking about disability, risk, patient advocacy, and feminist activism. As some ethnographic studies of biomedicine have pointed out, life preservation technologies intervene on non-biomedical cultural norms governing the meaning of life and death, the social significance of identifying the human form as a living body or dead corpse. Prenatal testing (Rapp 2002) and end-of-life decision making (Lock 2002; Timmermans 1999; Kaufman and Fjord 2011) have been particular targets of critique because of concerns that decisions made to start or end life are necessarily entwined with normative assumptions about whose lives are socially and economically worth continuing. These concerns are, in fact, materialized in the history of people with disabilities in the United States, who have frequently been harmed by policies of forced sterilization, institutionalization and de-institutionalization, and disinvestment in medical care and supportive social services. Given this history, technologies which make it possible to make a decision to end a life based on projected social productivity or the burden that may be placed upon others to care for the individual are viewed with both hope and suspicion. For people (including scholars) with disabilities and their allies, these issues are not merely scholarly thought experiments on the ontological status of the human body, but often arise as immediate life and death questions about their own lives.

This chapter’s discussion about stock epinephrine legislation further troubles these conversations. For mother-advocates pushing for state bills, the initial focus tends to be on *children* and targets the schools where they spend much of their days. On the one hand, these mothers espouse a desire for their children to be able to safely and fully participate in normal social life. Stock epinephrine requirements are seen as a way to allow food allergic children to attend school and fully participate in school activities with less worry and with a back-up safety net. On the other hand, they have selected school stock epinephrine legislation as the place to start because they know that society values the lives of children more than the lives of adults. The women I interviewed about this topic assume and have been told by more experienced activists and legislators that pushing for a costly measure to save children's lives will meet more success than pushing for costly measures to protect people of all ages with food allergies. While most in the food allergy community anticipate that protections will be expanded to more settings and to adults, targeting children was seen as the most foolproof first campaign. In short, while some of the rhetoric of these campaigns falls in line with disability studies thinking on life preservation, their political strategy embodies the worst nightmare of the field: differentially investing in some disabled lives over others.

Indeed, investment is a key dimension of stock epinephrine advocacy. Not only is investment in the future lives of children at stake; investment by the drug companies in the specter of future profits is also in play. Though much of what I learned about the involvement of Mylan was second-hand, the strategy is easily discernable, especially against the backdrop of previous research in STS and the unavoidable enthusiasm for digital health and biotechnology in New York City at this moment, where I am writing this dissertation. Investing in patient advocacy promises two ways to maximize profits for the enterprising pharmaceutical company: ensuring a steady stream of institutional customers for epinephrine auto-injectors now required by law to be purchased and kept on hand at all times, and ensuring access to the sentiments of patients and caretakers managing food allergies in everyday life. Their work drives the engines of what Sharon Kaufman calls “ordinary medicine”: they are transforming a formerly extraordinary, life-saving intervention into the cornerstone of public health approach to food allergies (Kaufman 2015).

The resources leveraged by pharmaceutical actors like Mylan put stock epinephrine advocates in what Kim Fortun (2001, 11) has called a “double bind”: the “fields of force and contradiction… the double binds that position enunciatory communities within new world orders." Here, the new world order in question is that of biomedicine. Though stock epinephrine advocates did not choose Mylan as a partner, and Mylan reportedly did not expect food allergy moms to already be active in the legislative realm, their extensive resources and lobbying expertise proved, in the end, useful additions to the grassroots campaign. As recent decisions on the rights of corporations to free speech drive home – including two recent decisions concerning the commercial speech of agents of pharmaceutical companies, *United States v. Caronia* (2012) and *Amarin v. United States* (2015) – the corporate partners with grassroots organizations have greater powers of enunciation in the United States today than the advocates themselves.

The unique character of the disease of food allergy also pushes on conventional ways of thinking about the nature of disability. The debility caused by food allergies – an anaphylactic reaction – is both unpredictable and avoidable. Yet it shapes a wide array of everyday habits and practices, as has been illustrated throughout this dissertation: the rules governing friendly and intimate physical contact, rituals and requirements for mealtime in the home and in public, and participation in the school day for children, just to name a few. In short, a food allergic person encounters the same sorts of social and institutional challenges faced by any person with a disability, but without any outward signs of the disease. Even the term “invisible disability” is a clumsy fit, as a person with food allergies can live with no symptoms at all – not even difficult-to-measure ones like pain – following diagnosis given the right conditions. Yet within the food allergy community, understanding the condition as a disability (though an invisible one) is a clear trend – largely as a strategy to ease access to the rights and privileges afforded by disability law in the United States, but also because it comes closest to reflecting the challenge of everyday life with food allergies.

What is disabling about life with food allergies, perhaps, is the sense that one is always at risk of catastrophic illness. As discussed above, an important driver of stock epinephrine legislation is the sense that these bills can mitigate future health crises, including the disaster of a child's death. As geographer Ben Anderson points out in his reading of Brian Massumi, "futures are present as epistemic objects, affects or materiality. However, they do not cease to be, in some way, absent in that they have not and may never happen" (Anderson 2010, 7). Certainly, parents of allergic children hope that episodes of severe anaphylaxis in schools affecting their particular children "have not and may never happen," but evidence from other children's deaths suggests that it is at least a small possibility. What results is a social movement for stock epinephrine legislation whose moral compass is set toward a fearful anticipation of future life and death. Stock epinephrine legislation turns an individual's need for "drugs for life" (Dumit 2012) into a public health mandate that anticipates a future of expanding allergic crises.

# CHAPTER 7

# CONCLUSION: FOOD ALLERGIES, MORALITY, BIOMEDICINE, AND HOPE FOR A CURE

After more than a century of biomedical research, food allergy remains a puzzling and challenging diagnosis. There are no reliable measures to prevent reactions besides avoiding the foods one is allergic to. The symptoms of the disease vary by person, by food, and by health status from moment to moment, making it difficult to predict who will be allergic to what, how much of a food will trigger a reaction, and how severe a person's symptoms will be today. People living with food allergies sift through a variety of etiological and disease models in an attempt to explain their condition, figure out who or what to blame, and understand how best to stop or prevent future cases. To date, however, the numerous theories about causation stubbornly remain statistical correlations with no concrete steps that individuals can take to guarantee protection from developing allergies.

To manage this incurable condition in everyday life, parents of allergic children and adults with food allergies vigilantly police their foods and environments. "The hygienic sublime," an ideal that equates certain practices of maintaining purity with safety, is a foundation of that approach. It is built upon traditional gendered divisions of labor in the home, but has been exported to commercial and industrial contexts, distributing responsibility for taking care of food allergic people beyond the individual and their immediate kin. A similar decentralization of responsibility is going on with the spread of stock epinephrine laws, which make it easier for bystanders to administer emergency medication to people undergoing allergic reactions. A moral commitment to protect and save human lives – especially the lives of children – motivates activists, corporate executives, physicians and researchers, non-profit staff, and ordinary people with the disease to get together behind these pillars of food allergy management in the current moment.

The moral framing of food allergy management and advocacy accomplishes certain things for my interlocutors and for my analysis. For my interlocutors, mothers making moral demands based on the extraordinary status of children has a particular urgency in American society. Children in middle-class, nuclear families are protected and shepherded physically, socially, and morally to adulthood, guarded all the while as singularly precious entities, norms with roots in Victorian bourgeois society. The demands of food allergy advocates to protect children in the absence of a surefire biomedical or technological fix proliferates social organizations (support groups, patient conferences, and non-profits), legal innovations (using disability legislation to protect children with food allergies), and business activities (the production of allergy-friendly food and the intensification of supply chain management). From an analytic perspective, observing the moral formations of this community allows for an understanding of what can be done when it seems like *nothing* can be done. Normative social formations, particularly normative gender and family roles, get deployed in this case, helping sufferers and caretakers to control social environments that pose physical threats to the bodies and social lives of people with food allergies. The lesson for the social analyst is that despite the apparent newness of the food allergy "epidemic," persistent forms of social organization are creatively adapted to manage an unexpected, unalterable, and persistent health crisis.

New treatments for food allergies are now under development in labs and hospitals around the world, which have the potential to change advocacy activity concerning the disease. These new scientific developments have been reported in the scientific literature only recently; their significance for patient advocacy is still unclear. Allergy immunotherapy, a technique first recorded in use in 1911 (Fitzhugh and Lockey 2011), provides the most immediate promise of a long-term reduction in allergic sensitization. Allergy immunotherapy involves introducing small amounts of the substance a patient is allergic to into their body. Over time, the immune system "learns" to recognize those materials as safe and lessens its response to their presence in the body. For environmental allergies, it does so by using under-the-skin (subcutaneous) injections or under-the-tongue (sublingual) drops. For food allergies, sublingual drops, skin patches, and simply eating controlled doses of allergens (called oral immunotherapy) are preferred. To date, clinical trials have been conducted quietly and on a relatively small number of patients, but the science of allergy immunotherapy is now poised to become a nexus of interest and contention in this community. Large Phase III clinical trials led by two key players in this area, DBV Technologies and Aimmune Therapeutics, were launched in December 2015 and January 2016 respectively and are expected to enroll hundreds of food allergic children with motivated parents. The debates documented here about responsibility for mitigating reactions and etiology may shift considerably or become totally moot if these treatments are successful for a large portion of patients, and are likely to be replaced by more quotidian (but no less important) debates about the cost of healthcare, the psychic burden of long-term medical therapies, and what it means to lose a carefully cultivated "food allergic" or "food allergy mom" identity.

In the meantime, people must make do with vigilant avoidance of allergenic foods. This dissertation has offered a snapshot of how people do so, and how this shared experience has become the basis for community and activism in the United States. The key players in this document are middle-class, mostly white mothers of allergic children; they have the time, resources, and motivation to better the world for their children. Mothers founded the organizations which today make up the food allergy non-profit industry, they liaise with pharmaceutical companies, resilient to the intimidation of their staff and lobbyists, and they continue to play important roles in new aspects of the movement like stock epinephrine legislation advocacy. Their concerns inflect the wider community, including physician interest in researching treatments that are most highly effective in children, staff at non-profits who use poster children to appeal for donations and activism, and specialty food companies that focus their resources on developing kid-friendly cookies, candies, and prepared foods. Their concerns about controlling the diets of their children are also shared with other disease communities, such as the celiac disease community and the community of parents of autistic children, for whom food also functions both as medicine and a source danger. Future research could further clarify these connections between illness activism, safety, and food.

Lost in the concern about children is that adults make up 9 million of the estimated 15 million people in the US with food allergies, and today's allergic children will be tomorrow's allergic adults. What of their experience and their needs? Throughout my research, I sought to speak with allergic adults as much as possible about their experiences. Given the epidemiological estimates, they are highly underrepresented in the community; even when they are present, they often go with the flow and focus on the needs of children. Jenna and Michael, featured in Chapters 4 and 5, are notable exceptions. The experiences of food allergic adults at work, traveling, birthing and raising children, and managing family gatherings are complicated not only by food allergies, but also by the normal breakdown of aging bodies and apparently high rates of co-morbid autoimmune conditions. Some of the relationships I built with allergic adults led to interviews and participant observation, but other encounters were too complicated to be compatible with the scope of my IRB approval, and therefore could not be featured here. Adjustments to my research strategy and scope could bring the experiences of food allergic adults more to the fore in future research. But while their contexts may be different, their core disease management strategies – investigating etiology and food supply chains, enlisting responsible caretakers in their communities, and so on – and the moral concerns surrounding them are similar in large part for people with food allergies throughout the lifespan.

While my research to date has focused on the food allergy community, the arguments this dissertation offers regarding how risk, responsibility, and blame become embedded in the everyday management of chronic disease offers lesson for other conditions and communities. Understanding these (and other) moral contours of the experience of chronic disease and the communities to which it gives rise is a newly popular way to understand the often traumatic effects of disease, impairment, and debility. Childhood asthma, developmental delays, autism, congenital physical differences, metabolic disorders, and childhood cancers and just a few of the early life conditions that other anthropologists are researching in work that remains unpublished so far. At the other end of the lifespan, the social and moral costs and opportunities of life-extending “drugs for life” (Dumit 2012) and heroic medical interventions at the end of life (Kaufman 2015) have long been an area of interest in medical anthropology. Epinephrine auto-injectors both speak to and challenge these uses of biomedical technologies. Kinship figures prominently, too: how to make, raise, and sustain kin is central to the families I got to know in my own research, and the impact of biomedical technologies on making and sustaining kin has reinvigorated research on this classic anthropological concern for nearly two decades. These life events and social ties shape the meanings and practices of biomedicine in many disease and life cycle contexts, including our assumptions about the right way to do care work, who is responsible for health, the management of risk factors, models of causation in human biology, and what it means to be “healthy” or “sick” in the first place.

## Locating Blame and Responsibility

A major interest throughout this dissertation has been to analyze who my actors think are to blame for allergies and responsible for managing allergic reactions. Practically, these concerns motivate assertions about who ought to be responsible for preventing and mitigating allergic reactions. As I have argued throughout, blame and responsibility are deeply moral issues. Asking who or what is to blame poses a question about who (else) is at fault – that is, who has done wrong, a characterization that is necessarily refracted through a moral logic of good and bad. Asking who is responsible for mitigating the risk of harm imposes a normative moral order on everyday activities and relationships, with certain actors assumed to be morally responsible and others let off the hook. The connection between risk and blame is made forcefully by Mary Douglas in her later-career writings on technology in Western culture, and her perspective animates the conception of risk that runs throughout this dissertation. Rather than only ask how notions of risk and danger are interpreted and then used to inform the production of safety in the context of food allergic living, I also ask, what more general cultural logics undergird these ideas?

In the food allergy world, the moral drama of everyday life with food allergies revolves around the responsibility of mothers to care for children. The logic of care (Mol 2008) in this case is highly normative, relying on traditional gendered divisions of labor concerning housekeeping, food preparation, and childrearing. Raising a child with a chronic disease like food allergies, where one wrong bite or accidental cross-contamination can lead to an episode of serious illness or death, heightens the sense of responsibility felt by food allergy parents, especially mothers. While early advocacy efforts focused on mothers offering support to each other in local communities, the now-national food allergy community in the US has decidedly shifted its focus to advocating for broadening the distribution of responsibility for care. Feminist literature critiquing the gendering of care and the social model of disability gives some traction for interpreting these issues. At stake are important questions about who ought to be responsible for caring for those considered vulnerable in society. Through their activities concerning stock epinephrine laws, food labeling requirements, and the classification of food allergy as a disability in educational settings, food allergy advocates seem to be arguing that providing care ought not be merely a private matter for kin to manage on their own, but a public concern backed up by the powers of the state.

This is, of course, fraught terrain in current social theory: state power promises the privileges of legal personhood and protections, but these boons are ensured by the enforcement of neoliberal tactics that discipline collectives and responsibilize individuals. Legal protections reinforce monadic individualism by assuming that the individual is a decision-making machine in whom responsibility for the self is located. This is deeply embedded in the legal logic of modern states, traceable to the legacy of Platonic mind-body dualism evident in Locke’s formulation of private property. For Locke, the basis of property is the individual’s possession of the body: “every man has a property in his own body: this no man has any right to but himself” (Locke 2001). Nowhere is the individual more privileged over the collective concerning decision-making and well-being than in healthcare. Yet rarely does the individual face more difficulty – physical, social, and psychic – when demanding and enacting the right to determine what happens to their own body than during serious illness. The moral drama of life with food allergies, and of resulting projects such as stock epinephrine advocacy, is one site of many where these inherited tensions are being negotiated in real time.

Documenting how legislation concerning healthcare is brought into being with the backing of disease sufferers and caretakers, as I do in the final chapter of this dissertation, reveals some of details of the moral logics surrounding the governance of health in the United States. When legislation and legal precedent intervene on ordinary life, the moral intentions of their enforcement becomes embedded in layers of procedure, precedent, and jargon. Yet studying legislation-in-formation makes clear how advocates strategically play with dominant moral orders to reach their goals. A silent consensus has united mothers, drug companies, and non-profit organizations around the strategic benefits of focusing on mothers and children in the push for stock epinephrine legislation. Innocent children are the emblem of stock epinephrine, appearing in press releases, on websites, and even testifying to state legislatures in person. Mothers are some of the most prominent public spokespeople for the movement, deploying traditional feminine charms – cheerfulness, deference, politeness – and speaking mainly on behalf of their children's safety to get what they want. Yet the goal of their efforts is to widen the circle of caretakers of their children in their local communities – teachers, coaches, priests, summer camp staff, shopkeepers in shopping malls and stadiums – to relieve the pressure on themselves to maintain the hygienic sublime on their own.

This state of affairs resembles what Kim Fortun (2001) calls a "double bind" of power and discourse, binding individuals to institutions (in this case, institutions as varied as the cultural institution of gender and corporate entities like Mylan) that may not have their best interests at the fore in order to accomplish what they need to live safely. Gender roles and capitalist labor arrangements have each been extensively conceptualized on their own as repressive apparatuses; together, their repressive potency multiplies. But both of these systems, like the system of risk unpacked in the introduction and empirical chapters, are also realities of everyday life that most people must routinely work with and through, as well as struggle against. The uneasy truce between leading food allergy advocates and Mylan representatives illustrates this well: corporate power and gendered performance are engaged strategically, to accomplish the end of protecting children – a highly normative goal in its own right for middle aged, middle class women. Though their tactics are effective, the uneasy outcome is that the effectiveness of their performance reinvigorates gendered expectations and gives a boost to Mylan's image as a morally responsible drug company. Problematic moral norms – women as (primarily) caretakers, drug companies as altruistic – persist, and are perhaps stronger since their enactment has been proven socially effective. In this case, advocacy sits uneasily with social theory.

Investigating and elucidating "the moral", especially in contexts of (health) care, has become a cottage industry within anthropology during the course of my research and writing. I see several ways forward that can leverage this newfound attunement to the moral dimensions of social life to ask and answer important questions about health and healthcare in the contemporary United States. For one, questions about and critiques of the distribution of responsibility for care are relevant in many contexts besides conditions where mothers are caring for children. Children caring for elderly parents is one; what happens when moral responsibility for care is removed from kin through the power of the state (as in children taken from their parents following abuse or substance use), economic and demographic reconfigurations, or sheer bad luck (when an elderly parent outlives their children) is another. There is more to understand about how legislation, non-legislative regulations, and everyday morality shape the logics and practices of care within institutional contexts from nursing homes to schools to prisons – a project taken up by Goffman in the middle of the 20th century and addressed obliquely in Foucault's later lectures, but whose context has changed so significantly that it is worth revisiting. Finally, and most relevantly to my own anticipated future work, there is a basic question about what place care has in contemporary biomedicine. Biomedicine is an industry with deep ties to finance capital as well as a set of caring practices; how do these moral orders conflict and become enmeshed? What are the actor-networks and models of social behavior that motivate how the business of care proceeds today?

## “Drugs for Life” and Eating for Health: Future Directions for Research

Sustaining health is big business in the United States, and it is a business built upon a particular model of what it means to be a “good” person. In the American context, health status and morality have long been connected, influencing everything from decisions about who can be a citizen, to policies concerning everything from transportation to food safety, to questions about the responsibilities the state has in managing the beginning and end of the life span. So much of the responsibility to be healthy is assumed to rest with individuals, justifying a relatively weak system of supports, rights, and privileges for people who need to or wish to use healthcare resources. Healthcare is also treated as a luxury consumer good, with prices and amounts of intervention said to be driven by a distinctly American desire for more of everything paired with an American ideological commitment to allowing supply and demand to set the cost of goods. We are told that these principles ought to apply even to goods that contribute to the maintenance of life. As a consequence, healthcare is extremely expensive for sick people to use, prices on particular goods and services are astronomical, and costs are distributed throughout the citizenry via insurance premiums and taxes. To be a good citizen in this context means not just to vote and respect the private property of others, but also to minimize the financial costs of sustaining one’s own life for the sake of the national purse.

In this moral-financial order of contemporary healthcare, one priority for future research is understanding the links between capital and the production of health-promoting knowledge and objects. What are the networks, moral norms, and logics that serve as a matrix for carrying out everyday activities in the healthcare industry? Allergy immunotherapy is an excellent example. Three small, independent biotechnology companies are now working on food allergy immunotherapy products. Nowhere is the capital investment *and* the moral imperative to produce more, new, and better ways to care for patients stronger right now than in biotechnology. New therapies that seek to modulate human immunity are expensive, risky, and time-consuming to develop (time during which executives and managerial staff must continue to be paid). While investors, company executives, and scientists can find ways to "de-risk" such investments on paper, therapies must eventually be tested in real human bodies with complex, poorly understood mechanisms of immunity. The regulatory expectations for this class of drugs underscores their special status in the pharmaceutical universe: the FDA's Center for Biologics Evaluation and Research (CBER), the division that regulates many products designed to modulate immune function, expects companies to have little understanding of a new drug's mechanism but to provide robust evidence of its clinical efficacy. This is a reversal of the priorities of other divisions of the agency. The predictable unpredictability of human immunity makes developing immunotherapies (for any indication) relatively quick to get to clinical trials and relatively straightforward to get to FDA approval, but especially vulnerable to the vicissitudes of human biology in clinical trials.

But the risk and expense are also the very things that make this kind of drug attractive to speculative investors. In investment logic among life science investment banks and high net-worth individuals, high risks of failure means high rewards for the few who succeed. This financial logic, along with many others that shape healthcare investment, may be fallible on their own terms, but the actors who make decisions about business strategy act as though they are true, enacting laws of supply and demand and risk management policies at the level of corporate governance. As much as ideals of healthcare as a force for good – what I tentatively call the “care thesis of biomedicine” – inflect how providers and patients use and encounter biomedical tools, the capitalist logics of what makes a “good investment” determine in large part the kinds of biomedical science, healthcare services, and products that are even made available on the market in the first place. Understanding how these two moral orders – the morality of investment capital and the care thesis of biomedicine – both counteract and become enmeshed with each other is an important next step for understanding how ordinary people experience the American healthcare system.

A second future avenue of research concerns the evolving relationship between food and health in the United States. “Eating for health” is a trend not only among food allergy families, but also among other illness communities and within certain fitness communities. The very nature of food allergies and the avoidance of allergens that forms the basis for managing the disease today means that biomedicine alone does not have all the answers. The American food system is understood to be culpable for the misfortune of food allergies (sometimes proximally as the cause of a particular reaction, sometimes distally as a systemic cause of the rising incidence of the disease), and therefore food systems, food production, food service, and dietary habits are targets for managing health as much as the internal biology of individual humans. These projects are ongoing in the food allergy advocacy world, with new rules currently being drafted to expand the number of “major allergens” that must be labeled and close loopholes that allow incomplete ingredient and food processing disclosures. These milestones may coincide with new biomedical recommendations about prevention and treatment of food allergies – they may come too late for those who are allergic today and may prove to be irrelevant to future generations. What will be the fate of food labeling legislative advocacy and awareness-raising efforts in the food service industry if the “epidemic” these projects are meant to make tolerable disappears by the time today’s food allergic children are allergy-free adults?

Health is about more than medicine. As this dissertation and concluding remarks have hopefully made clear, it is also a political cause, a moral imperative, a business, and a component of personhood. Kinship, capitalist production, biomedical knowledge about individual and species biology, gender roles, caretaking practices, and labor all influence how health is defined, sought after, sustained, and restored. Bodies – both healthy and ill – are the object of many of our hopes and fears for the future. The events that befall them over time become central to personal and community narratives that give voice to feelings of belonging and exclusion. What will be the fate of “the body moral” in this 21st century, the much-hyped century of biology?

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