

THE BIG SQUEEZE

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of Health Care Work*

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HANDEL REYNOLDS, MD

THE BIG

*A Social and Political History of the
Controversial Mammogram*

SQUEEZE

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*To my dear family, Marlene, Gevin, and Telissa
for their unfailing love and support*

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THE BIG SQUEEZE

INTRODUCTION

The Mammography Story

The story cried out to be told. It cried out in the passion of the true believers, apologists for a beleaguered test. It cried out in the polemics of the skeptics, emphasizing possible risks and advising caution. It cried out in the posturing of political leaders who co-opted a scientific debate to satisfy the expediency of the moment. It cried out in the gratitude and calm resignation of those for whom mammography worked. And it cried out in the silent pain and anguish of those who did “everything right,” yet for whom mammography failed.

Over the years, our national conversation on mammography has often resembled the ancient Indian parable of the blind men and the elephant. In this tale, each man feels just one of the animal’s body parts and tries to describe the essence of the beast. Thus, one feels the elephant’s sturdy leg and declares, “The elephant is much like a pillar.” Another feels its thin tail and concludes, “The elephant is much like a rope,” and so on. This book attempts to take a step back, remove the blinders, and tell the whole story.

From the beginning, mammography has been promoted as a silver bullet in the fight against breast cancer, the most important

thing a woman can do to “protect” herself from the dreaded disease. This “mammogram protector” metaphor has been a dominant theme in public education campaigns throughout the history of the test. It has been very successful in establishing a culture of screening. Yet this simplistic rendition of a complex issue has also had many undesirable effects. Most important, it has contributed to a pervasive misunderstanding of what mammography is and what it does. Many women overestimate mammography’s capabilities; others confuse *screening* with *prevention*. Thus, not surprisingly, anger and confusion are common responses when a woman is diagnosed with breast cancer despite faithfully undergoing annual testing.

Mammography has been mired in controversy since its earliest days. The question whether women under fifty should be screened first became a contentious debate in 1976, only three years after its nationwide debut. This dispute has dogged mammography throughout its existence, becoming more acrimonious with each eruption. There are two reasons for this. The first is that the debate has never been entirely about science. In this book I show that major stakeholders in this debate—namely, the American Cancer Society and the American College of Radiology—adopted a “pro” position on this question, long before there was any scientific basis for it. In the ensuing decades, it has become clear that the science supporting screening is much more robust for women over fifty (postmenopausal) than for younger women. Thus, in most of the developed world, public health policy calls for screening to begin at age fifty. In the United States, the backers of under-fifty screening succeeded by convincing political leaders that it was expedient to be on the “right” side of this issue. In taking that position, they would demonstrate appropriate sensitivity to women’s health issues. As this occurred, the nexus of the debate moved from the realm of science to politics. Here it has resided, at least since the mid-1990s. The second reason why the screening of women younger than fifty is mammography’s perennial dispute is that both parties in this argument claim to have

science on their side. Because there is some scientific justification for both positions, each side has taken to denouncing studies that conflict with its view and highlighting those that support it. Thus, over time, positions have become more rigid and uncompromising.

Now more than ever, women deserve an open and frank discussion of mammography, its benefits, and its potential risks. Not only does the controversy regarding under-fifty screening continue unabated, but also there is a growing body of research that questions whether decades of screening mammography has accomplished anything at all. These studies suggest that the observed reduction in the death rate from breast cancer is due to improvements in treatment rather than early detection. As we approach the fortieth anniversary of the start of widespread screening mammography in the United States, it is a fitting time to pause and reflect.

The Big Squeeze: A Social and Political History of the Controversial Mammogram chronicles the often turbulent history of screening mammography since its introduction in the early 1970s. This book makes five key points. First, it shows how pivotal decisions during mammography's initial roll-out made it all but inevitable that the test would never be far from controversy. Second, it describes how, at several key points in its history, the establishment of a culture of mammography screening was greatly aided by concurrent social and political forces and movements. Third, it illustrates how politics came to dominate the debate, eventually achieving primacy over science itself. Fourth, *The Big Squeeze* describes the collateral economy that developed around screening. As mammography was aggressively promoted in the late 1980s to early 1990s, utilization rates rapidly increased. As this occurred, the mundane mammogram became the little *pink* engine that could, and did, drive the growth of a vast screening-dependent secondary economy. Finally, mammography's burden, overdiagnosis, is considered in the last chapter. Overdiagnosis, the screening detection of cancers that would never otherwise have come to light in the individual's lifetime, is an

important yet woefully underdiscussed risk of mammography. This phenomenon is more significant than that, however. Overdiagnosis helped make fighting breast cancer the most favored disease cause and mammography the most favored weapon in the fight.

The story of mammography fascinates me for several reasons. First, no other medical test even comes close in the degree of passion and controversy it evokes. Between the true believers and the skeptics, the mammography debates of the past four decades have showcased the full range of human emotion. Second, no medical test has been so completely “adopted” by political leaders eager to demonstrate their sensitivity to women’s issues. They have not simply appropriated the debate, however; they have largely converted it from a scientific to a political one. Finally, and this may be the most fascinating point of all, the central argument in the disputes over mammography—namely, whether or not women under fifty should be screened—hasn’t changed in the entire forty-year history of the test. As a radiologist, I have witnessed the unfolding of this compelling history firsthand. Through *The Big Squeeze*, I wish to share it with you.

First, though, a word about definitions. Throughout this book the term “mammography” should be understood to mean “screening mammography.” This is a test that is performed on women without breast-related symptoms or complaints, to search for unsuspected breast cancer. In the United States it is typically performed at one- to two-year intervals on women, starting at age forty. This is the subject of the book. There will be occasional references to “diagnostic mammography.” This is mammography used to evaluate a specific problem the patient may have, such as breast pain or a lump. This test is done on an as-needed basis. It is not a central part of this discussion.

TIMING IS EVERYTHING

Screening mammography burst onto the stage of national consciousness in 1973. When it did, it found an audience primed to receive it. Political, social, and health movements that had been occurring in the larger American society underwent a remarkable convergence in the late 1960s to mid-1970s. This was precisely the time when the results of the earliest medical research on mammography were becoming widely known. Though it is likely that this new screening test would have been successful on its own, this fortuitous alignment of external forces helped ensure that public acceptance would be rapid and durable. In this chapter I examine the three principal movements that set the stage for screening mammography's auspicious debut. In its subsequent history, newer incarnations of these same forces would surface repeatedly, particularly at times of great controversy.

Cancer Fighting as Good Politics

On March 25, 1970, Senator Ralph Yarborough, a Texas Democrat, made an impassioned speech on the floor of the United States

Senate. In it he bemoaned the lack of significant progress toward the eradication of cancer in the thirty-three years since the establishment of the National Cancer Institute (NCI). Yarborough, who had been in the Senate for thirteen years, was a progressive southern Democrat who, as chairman of the Labor and Public Welfare Committee (now the Health, Education, Labor and Pensions Committee), was a frequent and forceful voice on health issues. As he saw it, the cause of this stagnation was twofold. Primarily it was due to severe under-resourcing of the effort. He pointed out that the approximately \$200 million per year being spent at the time on the government's anti-cancer efforts was "far less than the \$358 million we spend each year for chewing gum."¹ The second was the lack of a clear national focus and determination to accomplish the goal. To Yarborough and like-minded political leaders, the successes of the Manhattan Project and the Apollo program were apt case studies in what was possible when the nation was determined to spare no effort in order to achieve a seemingly impossible goal. Yarborough's conversations with leading cancer experts, notably Sidney Farber, a distinguished Boston oncologist and president of the American Cancer Society (ACS), led him to believe that a major breakthrough in cancer control was imminent. In fact, a few months earlier, at the November 1969 annual meeting of the ACS, Farber had urged a \$2 billion a year effort, modeled after the space program, to achieve cancer control. "Without naming the day or year, such a conquest is a realistic goal," he is reported to have said at a press conference.² Going much further, Yarborough and forty-six co-sponsors introduced a resolution calling for the creation of a Committee of Consultants on the Conquest of Cancer. The committee was charged with recommending "to Congress and to the American people what must be done to achieve cures for the major forms of cancer by 1976—the 200th anniversary of the founding of this great Republic."³ The Yarborough resolution was adopted by the full Senate and resulted in the constitution of a twenty-six-member Committee of Consultants, co-chaired by Far-

ber and Benno C. Schmidt, chairman of the board of the trustees of Memorial Hospital in New York.⁴

Nineteen seventy would prove to be Yarborough's last full year in the Senate. In May of that year he was defeated in the Texas Democratic primary election by conservative businessman Lloyd Bentsen Jr. in a particularly bitter political contest.⁵ The Committee of Consultants presented part one of its report to the Senate's Labor and Welfare Committee in the fall of 1970. Despite his recent electoral trouncing, Yarborough, in the final days of his Senate service, introduced a major piece of health care legislation. The Conquest of Cancer Act, introduced in December 1970, incorporated most of the major recommendations of the advisory committee. Its primary provision was to call for the establishment of an independent cancer-fighting agency, the National Cancer Authority (modeled after the National Aeronautics and Space Administration), which would take over all the responsibilities of the NCI but would not be a part of the National Institutes of Health.

At the White House the battle was about to be joined. President Richard M. Nixon, sensing that Congress had tapped into an issue likely to resonate with the American people, was not going to miss an opportunity to demonstrate presidential leadership. The public was becoming increasingly frustrated with the Vietnam War, and he was eager to change the subject of the national conversation. In his State of the Union message on January 22, 1971, he called for an extra \$100 million appropriation to "launch an intensive campaign to find a cure for cancer." At no previous time in American history had cancer received this level of presidential attention. Nixon went on to declare: "The time has come in America when the same kind of concentrated effort that split the atom and took man to the moon should be turned toward conquering this dread disease. Let us make a total national commitment to achieve this goal."⁶

Competing cancer-fighting bills were introduced and debated in Congress that year. A modified version of the Yarborough bill

was introduced by Senator Edward M. Kennedy, a Massachusetts Democrat, and a Nixon-backed bill was proposed by Senator Peter H. Dominick, a Colorado Republican. After a contentious yearlong legislative effort, the National Cancer Act of 1971 was signed into law on December 23. In his signing statement Nixon extended the now familiar military metaphor associated with the anticancer effort. Referring to new presidential powers granted by the act, he vowed that “the President will be able to take personal command of the Federal effort to conquer cancer.”⁷ Not only would he be commander in chief of a military battling an enemy in Southeast Asia, but also he would be personally leading the charge against an enemy much closer to home. It is in this regard that Nixon is commonly considered to have launched the nation’s “War on Cancer,” even though, as we have seen, the fight was well under way by the time he arrived on the battlefield.

The National Cancer Act provided massive new federal funding for the country’s anticancer effort (\$1.6 billion in the first three years) and significantly elevated the status of the NCI. Of all its provisions, however, one in particular, the allocation of \$90 million to fund cooperative cancer control programs with state or private agencies, would quickly prove pivotal in the establishment of mammographic screening.⁸

Feminism and Women’s Health

The women’s health movement of the 1960s and 1970s constitutes the fourth wave of what the sociologist Carol Weisman describes as a larger “mega-movement” in women’s health, a phenomenon that began with the women’s health component of the popular health movement of the 1830s and 1840s and continued through the women’s health political agenda of the early 1990s.⁹ Women of the baby boom generation entered the period of peak reproductive potential in the 1960s, and it was these women, primarily in their twenties

and thirties, who were the leaders of this movement.¹⁰ Not surprisingly, their primary concern was asserting control over their reproductive functions. This movement, which was intertwined with the feminist movement of the same period, was motivated by a viewpoint which held that women did not have ultimate control over their own bodies and their own health.¹¹ As noted by Sheryl Ruzek, author of a detailed history of this movement, “from the Supreme Court to the examining room, men were making fateful decisions about women’s bodies and their reproductive lives.”¹² Abortion was illegal in most states, and many had laws limiting the sale and distribution of contraceptives. To further its goal of reordering the balance of power between the male-dominated medical and political establishments and the masses of laywomen, the women’s health movement employed two main strategies: self-help groups and political action organizations.¹³ The Boston Women’s Health Book Collective, the most famous of the self-help groups, consisted of a group of laywomen who met regularly to commiserate about their feelings of “frustration, and anger toward . . . the medical [system and] . . . doctors who were condescending, paternalistic, judgmental and non-informative.”¹⁴ The groundbreaking self-help women’s health manual *Our Bodies, Ourselves* was published by this group in 1971. It presented detailed information, all of it obtained through the painstaking research of group members, on topics such as contraception, abortion, the female sexual response, and sexually transmitted disease, to an audience of women unaccustomed to frank treatment of such subjects. The self-help gynecology movement, begun in April 1971 by the feminist Carol Downer, taught women how to perform a speculum examination on themselves or other women.¹⁵ Self-help groups in Chicago formed a network of facilities (known simply as “Jane”) where laywomen provided safe (illegal) abortion services.¹⁶ Freestanding birthing centers and the concept of “natural” childbirth took root in various parts of the country as a response to what many women saw as the “medicalization” of childbirth.¹⁷

Important accomplishments of the women's health movement during this time include the Supreme Court decisions *Griswold v. Connecticut* (1965), which invalidated a Connecticut law that made it illegal for married couples to obtain or use contraceptives, and *Roe v. Wade* (1973), which invalidated a Texas law banning abortion, legalizing the procedure nationwide for the first time.

According to Weisman, "the Women's Health Movement created a cohort of women concerned about matters of health and health care and a network of organizations to sustain this activism."¹⁸ Although in the 1960s and 1970s the issue for these twenty- and thirty-year-old baby boomers was reproductive health, it was this same cohort of activist women, primed and ready for action, who would fight the mammography and breast cancer battles as forty- and fifty-year-olds in the late 1980s and early 1990s.¹⁹

Preaching the Gospel of Early Detection

For most of the twentieth century, the principal theme of public discourse on breast cancer was early detection. This arose from the prevailing medical view of cancer as, initially, a local disease that, if treated early and aggressively, could be cured. As early as 1894, William Halsted, the renowned Johns Hopkins University surgeon who pioneered the radical mastectomy, wrote that "cancer of the breast is a curable disease if operated upon properly and in time."²⁰ Whether by design or happenstance, Halsted's phrase "operated upon properly and in time" encapsulated the essence of the cancer education programs that would come to dominate the new century. The point was simply that surgery cures cancer, but *only* if the patient presents to the surgeon promptly. A May 1913 *Ladies' Home Journal* article titled "What Can We Do about Cancer?" put it bluntly: "No cancer is hopeless when discovered early. Most cancer, discovered early, is curable. The only cure is the knife. Medicines are worse than useless. Delay is more than dangerous; it is deadly. The one hope, and

a strong one, is prompt and radical operation; a half operation is worse than none at all.”²¹

Founded in 1913 by a group of surgeons, the American Society for the Control of Cancer (ASCC) was warmly received and fully endorsed by the larger medical establishment. From its inception, the dominant message of the ASCC was that surgeons could effectively treat (and cure) cancer in its earliest stages.²² Early on, cancers specific to women received particular attention. To reach the female public more effectively, the male-dominated ASCC established an all-female wing, the Women’s Field Army, in 1937. This organization, modeled after a military unit down to the military-style uniforms and insignia its members wore, became known as the “educational arm of the ASCC.”²³ At its peak, the Women’s Field Army had 700,000 members, each having paid a one-time enrollment fee of one dollar.²⁴ These large funds were used to finance a massive public education campaign consisting of mass meetings, lectures, radio broadcasts, and newspaper and magazine articles, as well as educational brochures. Women were the target audience, and the focus was breast and reproductive cancers.²⁵ The overall message was threefold: that cancer could be cured, that early detection allowed successful treatment, and that regular medical checkups for women, even when they were feeling well, were essential.²⁶

In 1944 the ASCC underwent a major restructuring incited by a prominent New York philanthropist and health care activist, Mary Lasker. In addition to a change in the governance of the organization, the ASCC was rebranded the American Cancer Society. Shortly thereafter the Women’s Field Army was integrated into the ACS and the organization adopted a new focus: securing funds for cancer research through charitable donations. Its initial fund-raising activities were wildly successful, and within its first year of existence the ACS became the largest nongovernmental funding agency for cancer research.²⁷

Promoting early detection, however, remained a major focus of the ACS. In 1948 it produced, *Life Saving Fingers*, the first educational film on breast self-examination (BSE). In it, a woman, undressed from the waist up, demonstrated the procedure. The film was narrated by Dr. Alfred Popma, a Boise, Idaho, radiologist who is credited with developing the first educational materials specifically describing the proper technique for BSE.²⁸ It was widely distributed and shown to packed houses in major cinemas.²⁹

In addition to films, the postwar period saw continued dissemination of the early detection message in articles and advertisements in the popular press, posters, and educational pamphlets. As noted by the historian Kirsten Gardner, many of these directly targeted women and used fictional characters who demonstrated “good/wise” or “bad/foolish” behavior by following or not following ACS recommendations for early detection.³⁰ A “wise” woman was one who noted a lump in her breast and quickly sought treatment. She was portrayed as happy and healthy. A “foolish” woman ignored her lump, not seeking care until it was too late. She was portrayed as depressed and dying. Thus, observes Gardner, “women’s behavior became the key variable in cancer control. . . . [I]f a woman with cancer failed to follow early detection principles, death seemed inevitable, and the victim assumed the blame.”³¹ There was little to no discussion of the difficulty and uncertainty inherent in examining breasts (limitations of early detection), the physical impact of radical mastectomy (the only treatment available at the time), or the possibility that death may still occur despite “wise” behavior (treatment failure). While this single-minded focus on early detection may have been well intentioned, calculated to empower women and replace fear with hope, it had unintended consequences, some of which still echo faintly today in the guilt many women experience when a cancerous lump is found by their doctor or on a mammogram—guilt for having “failed” at BSE by not finding it first.

At this point it is helpful to digress briefly and consider another important female reproductive cancer. The American Cancer Society's efforts against cervical cancer would come to define its approach to screening mammography some decades later.

In January 1928 George Papanicolaou, a Greek-born pathologist who had emigrated to the United States in 1913, presented some preliminary observations at the Third Race Betterment Conference in Battle Creek, Michigan.³² Papanicolaou, working at Cornell Medical College,³³ had obtained daily vaginal smears from a group of women and examined them microscopically for cellular aberrations. He showed that malignant cells and precancerous lesions could be detected with this simple technique. Papanicolaou's work aroused very little interest in the medical community for many years. Surgical orthodoxy at the time accepted open biopsy³⁴ as the only reliable means of diagnosing cervical cancer. In the 1930s and 1940s Papanicolaou's findings were reproduced by other researchers, yet there was limited adoption of the new technique. Major barriers to adopting the Pap test were lack of education among physicians and the lay public as well as absence of an infrastructure of professional cytotechnicians and pathologists trained in the technique.

With these considerations in mind, an ambitious five-year cervical cancer screening program was launched in 1952. Dubbed the Memphis Project, it was jointly sponsored by the Cancer Control Branch of the NCI, the University of Tennessee, and the Memphis branch of the ACS. The goal of the project was to screen all 165,000 women over the age of twenty in the Memphis–Shelby County, Tennessee, area annually for five years.³⁵ The ACS and its army of volunteers played an important role in the public education component of the project.³⁶ During the course of the study, over 150,000 women were screened, and a large number of early stage cervical cancers were diagnosed. Prior to the initiation of screening, 34 percent of white and 18 percent of African American cervical cancer patients in the Memphis–Shelby County area were diagnosed in

stage 1. During the program, these rates increased to 57 percent and 38 percent, respectively.³⁷

The success of the Memphis Project showed that the Pap smear could be efficiently applied to large populations, that early detection of cervical cancer was possible, and thus lives could be saved.³⁸ In 1953 the U.S. death rate from uterine cancer (including cancer of the cervix as well as the body of the uterus) was 16.8 per 100,000 women. By 1963 the death rate had been reduced by a remarkable 27 percent, to 12.2 per 100,000.³⁹ This notable achievement was largely due to widespread adoption of the Pap smear in routine gynecologic care. The Pap smear represents the most dramatic validation of early detection in the history of medicine. These efforts were viewed as unmitigated triumphs of the principles long espoused by the ACS. The elixir of success strengthened its resolve and bolstered its confidence.

Thus, by the time screening mammography was introduced to the public in the early 1970s, the notion of early detection for effective cancer control had been successfully inculcated in the American psyche. The new screening test promised to be more reliable than the patient's fingers and would lighten the burden that self-examination placed upon her. The ACS, hoping to reproduce its success against cervical cancer, would again play a leading role in the dissemination of a new screening technology. Add to this the new cancer-fighting political agenda in Washington, D.C., and the growing women's health care activism, and the stage was set for screening mammography to have a successful opening act.

FIRST EXPOSURE

In medicine, the introduction of new imaging technology is typically a three-phase process.¹ In the first phase, diffusion occurs slowly as early adopters—academics and other “technology leaders”—perform much of the initial clinical research that defines the capability of the new device. If these results are favorable, then as they are disseminated in medical journals and professional conferences, there comes a point when a rapid increase in the adoption of the new technology is observed. This second phase is often aided by media attention, which in turn drives consumer interest. Finally, as market saturation is achieved, the rate of diffusion levels off.

Mammography’s path was not so orderly or predictable. In 1970 the age-adjusted death rate from breast cancer in the United States stood at approximately 27 per 100,000 women, essentially unchanged since record keeping began in 1930.² All the efforts of the first half of the twentieth century, promoting early detection and prompt radical surgery, had accomplished very little. When the American Cancer Society launched the massive Breast Cancer Detection Demonstration Project (BCDDP) in 1973, most Americans had never heard of mammography. Their first exposure would be a crash course.

The BCDDP: A New Screening Regimen Emerges

Mammography was not new in 1973. Like the Pap smear, it had languished through a prolonged season of indifference. Clinical mammography (that is, on live patients) was first reported by Stafford Warren in 1930.³ In the 1930s and 1940s there were sporadic other reports of clinical mammography in the medical literature. These all described using X-ray to examine the breasts of patients who were already suspected of having breast cancer because of the presence of a lump or other symptoms. High-quality images were very difficult to obtain, however, and the technique was hard to reproduce outside select research institutions. Mammography never caught on.

Interest in mammography was renewed as a result of two important developments that occurred in 1960–61. In 1961, the radiologist Jacob Gershon-Cohen, of Albert Einstein Medical Center in Philadelphia, reported on his findings from mammography in healthy women (that is, with no physical signs or symptoms of breast cancer). In 1956 he had recruited 1,312 such women, who then underwent mammography and physical examination every six months for five years. During the course of the study, twenty-three cancers were discovered, six of which could not be palpated on physical examination but were identified solely on the basis of the mammographic findings.⁴ This study was significant for two important reasons: it was the first use of mammography as a screening tool (that is, to evaluate women who had no suspicion of breast cancer), and it was one of the first demonstrations that mammography could identify breast cancer that could not be felt by a surgeon.

At about the same time that Gershon-Cohen was initiating his screening study in Philadelphia, another radiologist, Robert Egan, was completing his radiology training at M. D. Anderson Cancer Center in Houston. His department chairman had assigned him the task of solving the technical problems of mammography. By vary-

ing the intensity and quantity of the radiation used, as well as experimenting with a variety of different X-ray film types, Egan's work produced the technical breakthrough that mammography needed. When he published his results in 1960, he described the technical factors required to produce high-quality mammograms reliably. Using his technique, one thousand mammograms were performed on women suspected of having breast cancer. Not only was he able to identify correctly 238 of 240 known malignant tumors, but also he identified 19 tumors in breasts that were thought to be normal on the basis of the surgeon's physical examination.⁵

As an aside, it should be noted that at this stage in its history, mammography was performed with general purpose X-ray equipment, such as might be used to X-ray a broken bone. Machines designed specifically for mammography, such as we have today, were not introduced in the United States until 1967, when the French medical equipment manufacturer CGR unveiled the Senograph. By the early 1970s, there were multiple manufacturers selling similar *dedicated* mammography machines.⁶ The practice of using general purpose X-ray equipment for mammography did not completely disappear, however, until the late 1980s.

In the mid-1960s, the U.S. Public Health Service undertook a study in which radiologists from twenty-four institutions around the country went to M. D. Anderson to learn the Egan technique and were then observed to see if they could reproduce it in their own institutions. The results showed that the technique was highly reproducible.⁷

The momentum was building. In 1962 Dr. Philip Strax, director of radiology at City Hospital in New York, approached the leadership of the Health Insurance Plan (HIP) of Greater New York, a private health insurance company, with the results of Gershon-Cohen's and Egan's work.⁸ Strax, whose first wife, Bertha, had died of breast cancer at age thirty-nine, was very passionate about the disease. He had studied the Egan technique and had been offering

mammography as part of his practice. He felt strongly that the time had come for a large, carefully designed study of the effectiveness of mammography as a screening test for breast cancer. Coincidentally, the National Cancer Institute was interested in funding such a study and was looking for a suitable site.⁹

The HIP mammography trial began in 1963. It was directed by Strax; Sam Shapiro, an internist with the HIP research and statistics department; and Louis Venet, a surgeon at New York Medical College. In this study, 62,000 women between the ages of forty and sixty-four were randomly assigned to one of two groups. The screening group received mammography and physical examination at enrollment and at three subsequent annual follow-up visits. The mammography was a modification of the Egan technique. The control group received only the usual medical care, which at the time did not include routine mammography. The results, reported in the *Journal of the American Medical Association* in March 1971, were dramatic.¹⁰ After three and a half years of follow-up, there were 40 percent fewer breast cancer deaths among women aged fifty to fifty-nine who were in the screening group than among those in the control group. Furthermore, 70 percent of women who had their cancer diagnosed by screening had no disease in their lymph nodes, compared to 45 percent in the control group, indicating that screening caught the disease earlier, before it had spread. Finally, of the 127 confirmed breast cancers in the screening group, 42 (33 percent) were found by mammography alone.

The HIP trial was the first scientific validation of the concept of mammographic screening. At this writing it remains the only mammography study of its kind (a randomized controlled trial) ever performed in the United States. It is important to note that the benefits of screening were seen only in women fifty to fifty-nine years old. No benefit was demonstrated for women sixty to sixty-four or forty to forty-nine. These limitations did not dampen the enthusiasm

with which the results were greeted when they were presented at the American Cancer Society's Second National Conference on Breast Cancer in Los Angeles in May 1971.¹¹ To the ACS, it was starting to feel like Memphis all over again.

It was sometime shortly thereafter that Philip Strax approached ACS Vice President for Medical Affairs Dr. Arthur Holleb with a bold vision of an ACS-sponsored nationwide program of free screening mammography.¹² Not needing much convincing, the ACS board of directors formally endorsed Strax's vision in February 1972.¹³ The Breast Cancer Detection Demonstration Project, in its original version, called for the establishment of twelve individual detection projects, three in each of the four ACS administrative divisions (East, South, Midwest, and West). Each was to enroll ten thousand healthy women, aged thirty-five to seventy-four, for free annual screening consisting of physical examination, mammography, thermography (a technology based on sensing temperature differences in various parts of the breast as means of identifying cancer),¹⁴ and instruction in breast self-examination.¹⁵ A budget of \$2 million was established to fund the program for two years. With the recent signing of the National Cancer Act, large sums of federal funds, designated for cancer control programs, were ready to be disbursed. Perceiving an opportunity to do something on a truly grand scale, in 1972 the ACS formally proposed to the National Cancer Institute that the BCDDP be a jointly sponsored program.¹⁶ The new NCI-ACS demonstration project was to be the first major cancer control program in the nation's new War on Cancer.¹⁷ Its reach was more than doubled, to twenty-seven geographic locations (two sites ran two detection projects each, for a total of twenty-nine individual projects), and its budget tripled to \$6 million, with the ACS providing one third and the NCI two thirds. With the dramatic increase in the proposed number of centers, the number of expected participants grew to 280,000, and the period of screening was increased to five years.

The decisions to perform a demonstration project, as opposed to a true research trial, and to screen women as young as thirty-five years old have been widely debated in the decades since the BCDDP. A demonstration project is typically undertaken once the scientific validity of the intervention (here, screening mammography) has been firmly established.¹⁸ It is done to show how a test of proven value may be widely implemented. At the time, the only scientific validation of screening mammography was the HIP trial, and it had shown benefit only for women in the fifty to fifty-nine age group. It is clear that the main goal of the effort was simply to demonstrate that mass population screening with mammography was feasible and practical.¹⁹ It is also clear that some NCI scientists had misgivings about the lack of a scientific orientation to the BCDDP.²⁰ Women thirty-five to forty-nine years old were recruited for screening despite the absence of evidence that screening would benefit them. The sense of the ACS was that if screening worked for women fifty to fifty-nine, it would probably work for women of all ages, so its use should not be restricted. Recalling the early days of the program, Arthur Holleb, chief medical officer of the ACS from 1968 to 1988, noted in a 1992 article, "The HIP study showed an early benefit of screening in women beginning at 50 years of age, but the . . . American Cancer Society believed that the BCDDP should begin screening at age 35 years of age because more years of life might be saved."²¹ One can only surmise that Philip Strax's own experience of losing his wife to breast cancer at such a young age helped inform this decision.

The first three BCDDP centers were designated in January 1973, and by February 1974, all twenty-seven had been publicly announced.²² By the time the first patients were screened in July 1973, the ACS had already mobilized its vast nationwide army of volunteers, numbering 2.5 million at the time.²³ This massive effort was run out of local ACS chapter offices and involved working with women's clubs as well as utilizing radio, television, and newspaper

advertising. As with all successful grass-roots campaigns, it was the person-to-person contact that proved most effective. Forty-four percent of BCDDP participants stated that they had heard about the program from a friend, as opposed to 29 percent from the newspaper, 11 percent from television, and 9 percent from their physician.²⁴ By early 1974 there were reports of sites receiving two hundred telephone calls per day from women eager to participate. Nationally, appointment wait times grew to between three and six weeks.²⁵

In the fall of 1974 the BCDDP received an unexpected boost. On September 28 President Gerald Ford, at the conclusion of an economics conference, announced to the nation that his wife, Betty, had been diagnosed with breast cancer and had just undergone a radical mastectomy.²⁶ The tumor in Mrs. Ford's right breast had been found during a routine medical checkup days before. She would later credit early detection for her excellent prognosis. Approximately three weeks later, on October 18, Vice President-designate Nelson Rockefeller disclosed that his forty-eight-year-old wife, Margaretta (Happy), had undergone a mastectomy the previous day.²⁷ Mrs. Rockefeller had identified a lump in her left breast on self-examination two weeks earlier. Rockefeller stated that his wife's recognition of the lump had been aided by a "heightened consciousness" following Mrs. Ford's surgery.²⁸ The lump was confirmed by a visit to her gynecologist, who ordered additional testing, including a mammogram.

While neither Betty Ford nor Happy Rockefeller had her breast cancer detected by a *screening* mammogram, the intense media attention surrounding their diagnoses caused a surge in interest in mammography. BCDDP centers and non-BCDDP mammography facilities were overwhelmed with women demanding a mammogram. This intensified interest extended even beyond the usual demographics. College women, on the advice of campus health officials, began undergoing screening mammography in large numbers.²⁹

Significantly aided by this Ford-Rockefeller effect, the BCDDP completed the initial round of screening on 270,000 women in the first two years of the program.³⁰ As a result of this spike in screening rates, there was a 14 percent increase in the incidence of breast cancer in the United States during 1974–75. Those were the heady early days of mammography. The new screening test had rapidly achieved widespread public acceptance. There was a fresh sense of optimism about the potential of modern medical technology to conquer breast cancer. Mammography’s “new car smell” would not last long, however. Already the faint funk of approaching controversy was in the air.

The Summer of '76

Two public health issues, swine flu and mammography guidelines, dominated the nation’s attention during the summer of 1976. The first involved growing skepticism about a poorly conceived government plan to inoculate all Americans against a novel swine flu virus. This new virus had caused an outbreak at Fort Dix, New Jersey, in February of that year, sickening five hundred and causing one death. Fearing a repeat of the 1918–19 worldwide flu pandemic, the Ford administration immediately decided to begin development and testing of a vaccine against the virus—this even though there was no evidence of a developing epidemic in the months following the Fort Dix outbreak. The inoculation program eventually ended in disaster that fall after deaths and paralytic illnesses were linked to the vaccine.³¹

The second public health firestorm that summer was one that had been smoldering behind the scenes for several months. In September 1975 Dr. John C. Bailar III, NCI deputy associate director for cancer control, met with NCI director Dr. Frank Rauscher Jr. Bailar, a physician and biostatistician, had become increasingly concerned about the risk of radiation-induced breast cancer posed by BCDDP mammography, particularly to younger women. He had

been making public statements about the issue for several months and had already presented the results of his analysis at the May 1975 meeting of the American Association for Cancer Research. To address Bailar's concerns, Rauscher appointed three expert committees to review the scientific underpinnings of the BCDDP. One of these, chaired by Dr. Arthur Upton, would study the issue of radiation risk.³²

At this point the controversy was mainly taking place behind the scenes, an argument among researchers. There was very little public engagement on this issue. Yet the ACS felt that Bailar's assertions were a significant enough threat to the BCDDP that a joint press conference with the American College of Radiology was held in November 1975 to showcase positive early results from the program and to rebut Bailar's criticisms.³³ This incident illuminates two important dynamics in the evolution of screening mammography. First, early on, radiologists and the ACS created a formidable alliance in the advocacy and promotion of mammography. In fact, radiologists have always had a close relationship with the ACS. Six presidents of the ACS have been radiologists, including Dr. Justin Stein, whose term (1973–1974) coincided with the launch of the BCDDP.³⁴ This alliance has remained strong and has been a reliable bulwark through every crisis screening mammography has endured to this day. Second, these crises have frequently resulted in a stand-off between the American College of Radiology and the ACS on the one hand and statisticians and epidemiologists on the other, passionate true believers versus dispassionate truth-seekers.

Bailar published "Mammography: A Contrary View" in the *Annals of Internal Medicine* in January 1976.³⁵ In it he detailed his analysis of the radiation hazards associated with screening mammography. He worked from what was known about breast cancer incidence rates in populations of women exposed to high doses of radiation, such as atomic bomb survivors, and extrapolated down to the lower doses associated with mammography. While Bailar was

most concerned about the effects of radiation on younger women, whose breasts are more radiation sensitive, he ominously concluded, "Regretfully . . . there seems to be a possibility that the routine use of mammography in screening asymptomatic women may eventually take as many lives as it saves."³⁶ At around the same time, consumer activist Ralph Nader's Health Research Group uncovered documents showing that seventeen of the fifty-seven BCDDP mammography machines were producing radiation exposures in excess of program guidelines. The machine at the Georgetown University center in Washington, D.C., was delivering three times the maximum allowed radiation dose.³⁷

These revelations and dire forebodings caused quite a stir. In March 1976 new BCDDP participant consent forms, for the first time describing the risks of radiation, were approved and quickly implemented.³⁸ These forms would be revised several more times that year, each time to expand on the issue of radiation risk. By the time the NCI convened a BCDDP project directors' meeting on July 15, 1976, to hear preliminary reports from the three expert panels, Bailar's warnings had already been widely disseminated in the lay press. By August the mounting public criticism of the BCDDP had government health officials on the defensive. New interim screening guidelines were hastily adopted by the NCI and ACS. The new guidelines reported that, on the basis of the work of Upton's panel, a single mammogram was believed to increase a woman's risk of breast cancer by 1 percent over her lifetime. Citing the benefits shown in the HIP study, the guidelines reaffirmed continued mammographic screening for women over fifty. Regarding younger women, however, the guidelines flatly stated, "We cannot recommend the routine use of mammography in screening asymptomatic women ages 35-49 years in the NCI/ACS BCDDP."³⁹

If Betty Ford's and Happy Rockefeller's disclosures were the "action" of Newton's third law of motion, John Bailar's assertions were the "equal and opposite reaction." Almost immediately, enrollment

at BCDDP sites saw a precipitous decline of up to 40 percent.⁴⁰ The possibility of mammography causing cancer prompted women of all ages to steer clear of the test. Not only were healthy women avoiding *screening* mammography, but also women with breast lumps who needed *diagnostic* mammography for evaluation of their symptoms were refusing the test.

Almost as soon as the new guidelines were published, it became clear that the ACS did not agree with this near-total prohibition on screening younger women. ACS officials resorted to an interesting tactic of simply defining womanhood between the ages of thirty-five and forty-nine as a risky state of being. Both its chief medical officer, Dr. Arthur Holleb, and its president, Dr. Benjamin Byrd Jr., were repeatedly quoted in lay publications making the dubious argument that up to 80 percent of women in that age group are in one or more high-risk categories and should be screened.⁴¹ In a 1977 *Reader's Digest* interview, Byrd was asked, "How often should mammograms be done?" His response: "Mammograms should be done at the physician's discretion in women with a higher than normal risk of breast cancer. . . . In NCI-ACS experience, about 80% of women 35-50 meet one or another of these criteria."⁴² Philip Strax, who ran one of the BCDDP sites in New York, promoted his own guidelines. Among his reasons for screening younger women was that "women who are worried about breast cancer . . . need [mammography] to prove they do not have the disease."⁴³

Undeterred, the NCI tightened the restrictions further in May 1977, when it issued a modification of the interim guidelines. This modification allowed screening mammography in women aged thirty-five to forty-nine *only* if they had a personal history of breast cancer or had a mother or sister with the disease. Adherence to the new guidelines was made a contractual requirement for sites to continue participating in the BCDDP.⁴⁴

The controversies surrounding the BCDDP led to the convening of the first National Institutes of Health (NIH) Consensus

Development Conference. Known officially as the NIH/NCI Consensus Development Meeting on Breast Cancer Screening, it was held September 14–16, 1977, and was open to the public. At this forum the final reports from the three expert committees established in October 1975 were presented. In addition, a fourth committee, chaired by Dr. Oliver Beahrs, presented results from a detailed review of the BCDDP. The Beahrs Report made several important recommendations. First, it recommended continuing the BCDDP as a demonstration project, as opposed to trying to convert it to a randomized controlled trial, as some had suggested. Second, it placed added restrictions on mammographic screening in women under fifty. Women between thirty-five and thirty-nine should undergo screening *only* if they had a *personal* history (not just a family history) of breast cancer. It reaffirmed the modified interim guidelines that allowed mammography screening for women forty to forty-nine who had a personal or a close family history of the disease. Third, it recommended that more randomized controlled trials, like the HIP, be conducted to find answers to questions that the BCDDP would never be able to answer. Questions such as the value of screening in women forty to forty-nine years of age and the optimum interval between screenings were highlighted.⁴⁵ The recommendations of the Beahrs Report were largely endorsed by the conference panelists. Significantly, the age-related mammography restrictions remained the official BCDDP policy through the remainder of the program.

Before concluding this chapter, I want briefly to consider one more public health issue that had its origin in the summer of 1976. This crisis, though, would not come to light until 1981. Epidemiologists with the U.S. Centers for Disease Control would later trace the earliest appearance of the AIDS virus in the United States to a small group of individuals, friends and lovers who, in the summer of 1976, were living in close proximity to one another in the West Village neighborhood of New York City.⁴⁶ The devastation wrought

by this disease would give rise a decade later to the militant AIDS activism of the late 1980s, which in turn led to the rise of breast cancer activism in the early 1990s. This phenomenon was pivotal in the establishment of screening mammography in American culture and will be the subject of a later chapter.

THE AFTERMATH

Screening in the BCDDP was concluded in 1981, and the first results were published the following year.¹ Despite, or possibly because of, the controversy that had ensnared the program through much of its course, its sponsors proudly highlighted its accomplishments. Just over 280,000 participants had enrolled in the program, and about half (51.7 percent) completed all five screening rounds; 4,443 breast cancers were diagnosed. Of these, 3,557 diagnoses (80 percent) were directly attributable to screening (mammography or physical examination). The remaining 886 cases came to light either between annual screening visits or sometime after the participant completed the final round of screening. Of the 3,557 screening-detected cancers, 41 percent (1,481) were found on mammography alone. In the older HIP study, 33 percent of the screening-detected cancers were found on mammography alone. Among women fifty to fifty-nine years old, 41 percent of cancers in the HIP study and 42 percent in the BCDDP were detected by mammography alone. In women forty to forty-nine years old, 19.4 percent of cancers in the HIP were based on mammographic findings alone. In the BCDDP, this figure was nearly double, at 35.4 percent.

At surgery, 80 percent of BCDDP screening-detected cancers were found to have no involvement of lymph nodes, compared to 70 percent in the HIP.

Because the BCDDP was not designed as a scientific study, there was no control group of women who *did not* undergo screening. For that reason the BCDDP results could shed no light on the question of whether or not screening resulted in fewer breast cancer deaths (mortality reduction). Yet *mortality reduction* is the generally accepted standard by which the efficacy of a screening test is judged. If fewer screened than unscreened individuals die of the disease, the screening test can be declared effective.

These limitations notwithstanding, the ACS drew two critical conclusions from these early BCDDP data. The first was that the mammography of the 1970s was far superior to that of the 1960s. The rate of cancer detection in younger women, the percentage of cancers detected solely on mammography in women both over fifty and under fifty years old, and the rate of lymph node involvement were all significantly improved in the BCDDP versus the HIP. Second, it was therefore reasoned, since screening with the antiquated HIP mammography demonstrated a clear-cut mortality reduction for screened women over fifty, one could *assume* that such a mortality reduction would accrue to younger women as well with the use of modern mammography technology. The fact that the BCDDP's design could never positively prove this assumption did not hinder its acceptance.

The BCDDP's Legacy

In the history of mammography in the United States, the BCDDP was a seminal event. What the BCDDP *represented*, however, was as important as what it accomplished. As elegantly described by sociologist Maren Klawiter, the BCDDP represented a shift of the "mammographic gaze" into asymptomatic populations.² The shift began