
Introduction

Connecting Lives, Texts, and Social Change

This book tells a story about women who attained legendary status in the annals of medicine. They were exposed prenatally to what was promoted as a benign and exciting new wonder drug prescribed to millions of American women to prevent miscarriage from the 1940s to the 1970s. This new reproductive technology—the synthetic estrogen DES—proved to be ineffective in preventing miscarriage, and in the long run it has had profound and damaging consequences for children, especially daughters of the women for whom it was prescribed (Dieckmann et al. 1953; Giusti, Iwamoto, and Hatch 1995). In 1971, medical scientists observed an association between prenatal exposure to DES and a rare form of vaginal cancer (clear cell adenocarcinoma) in women under age twenty; using available medical categories, they identified this synthetic estrogen as the first “transplacental carcinogen” (Herbst, Ulfelder, and Poskanzer 1971). “DES daughters,” as these women are now called, are also at risk for poor reproductive outcomes, including ectopic pregnancy, miscarriage, premature birth, and stillbirth (Giusti, Iwamoto, and Hatch 1995). Almost forty years later, DES-related cancer remains rare, but reproductive tract problems—including menstrual irregularities, poor reproductive outcomes, and structural or cellular anomalies—are common among DES daughters (Fisher 1999; McLachlan 2006).¹

The 1971 study linking DES and clear cell adenocarcinoma was pivotal for women and for biomedical scientists and clinicians. The risks and damaging consequences of their prenatal exposure sent DES daughters and their

physicians on an unanticipated journey through medical practices that could not adequately address the DES-related reproductive tract cancer, infertility, and uncertain health effects that could appear at any time during their lives. After 1971, DES daughters and their mothers began to participate collectively as well as individually in DES regimes of practice, and in so doing they reconfigured the political landscape with consequences for DES daughters, the doing of science, and the practice of medicine. Joining together to found the grassroots organizations DES Action (1975) and the DES Cancer Network (1982), activists challenged existing medical and scientific knowledge about DES, often judging science based on their intimate, firsthand knowledge of their own bodies. They also developed alliances with medical scientists to pursue funding and support for DES research, screening, and treatment programs. Their compelling spoken, written, and visual narratives are at the heart of this book.

These stories capture the uncertainties, disappointments, struggles, hopes, fears, victories, pain, and joy of DES daughters. They also display how, individually and collectively, DES daughters drew from cultural resources and put “together in novel ways bits and pieces of what they found at hand” to create new knowledges, institutions, and practices (Layne 2003, 236–237). One of these new knowledges was rooted in their embodied experiences. Taken together, DES daughters used what they had and created a different kind of social movement, one that actively contributed to the development of transformed relationships of power and knowledge, not only in the history of DES and care for DES daughters but also in the politics of women’s health more generally.

The key to understanding DES is connecting these three important frameworks (feminist health scholarship, embodied health movements, and narrative). Each is necessary but not sufficient. Throughout the book, these three frameworks weave the story together, although the emphasis differs from one chapter to the next. As a result, this book is not just another story of an embodied health movement, just another narrative analysis, or just one more feminist study of women’s health—it is an amalgamation of these frameworks in and through DES daughters.

Feminist Health Scholarship

The stories these women tell and show highlight another unanticipated journey, about how we as feminist scholars understand and theorize power and knowledge. In the 1970s, a narrative of feminist health scholarship told of an “old regime” of power: controlling doctors at the top of a medical hierarchy wielding

power over women patients.² “Old regimes” of practice consist of heroic physicians making diagnoses rapidly, knowing the medical literature so well that the latest developments reported therein can be “photographically recalled,” and quickly transforming a critical medical problem into a biologically sound technical solution. Heroic medicine is active, decisive, and innovative. The moments when a doctor acts heroically are “the high points of medical training, medical practice, and medical history” (Apfel and Fisher 1984, 115). In heroic medicine, the body becomes “a battlefield, with good doctors fighting the good fight against bad bugs” (Todd 1994, 122). Old regimes of practice gained ascendancy in the early twentieth century. In this golden age of medicine, which reached its pinnacle in the 1950s, physicians had knowledge and expertise; patients did not, and thus, in this world, “an active doctor and passive patient agree[d] ‘the doctor knows best’” (Todd 1994, 122). This view of sovereign power was later challenged by a different feminist model of power and knowledge, often inspired by the scholarship of Michel Foucault, which tells about “new regimes” in which power is not held but exercised, develops in multiple locations with multiple strategies, and circulates through the body politic.

New regimes of practice are characterized by webs instead of central decision-making points; thus, there is often no clear “headquarters” or individual male doctor to oppose. New regimes of practice consist of multiple kinds of treatment and multiple caregivers and practices within clinics as well as alternative and complementary treatments and caregivers outside conventional clinics (Klawiter 2003, 2004). Direct-to-consumer advertising, informed-consent legislation, managed-care regulations, and insurance-reimbursement policies also imbue the new regimes. Multiple sources of information can include Internet access to scientific literature, critical interpretations of the literature, chat rooms, and patient movements and organizations. Knowledge and decisions about the clinical contours of disease and public discourses emanate from local and unstable locations. Power is “exercised from innumerable points, in the interplay of nonegalitarian and mobile relations” (Foucault 1978, 94) instead of being exclusively vested in individuals or institutions. That is, power is “automatically ‘built in’ and mobile, *embodied* through social practices and norms” (Clarke et al. 2009, 3–4, emphasis in the original).

This new kind of revisionist investigation by feminist health scholars, within the context of organizational changes in medicine and society, paid more serious attention to the spoken and written words of practitioners and patients inside and outside the consulting room. Feminist scholars and activists have uncovered ways in which women patients have been active agents and not just passive recipients of medical sovereignty and in which medicine has been beneficial to women, as well as tensions, contradictions, ambiguities,

and uncertainties in medicine itself.³ They have shown how metaphors from the broad society and from within scientific and medical research communities move back and forth, blurring the lines between “outside” and “inside.” This scholarship reveals complex webs of power and mobile and transitory points of resistance that have produced shifting, fracturing, and regrouping cleavages (see Foucault 1978, 94).⁴

Feminist health scholars have written different narratives about power and knowledge even as they have challenged and brought changes in regimes of practice. Whereas old regimes of practice were dominant in the 1960s and 1970s, and new regimes of practice began to dominate in the 1980s, I argue that the stories of DES daughters display how the workings of power are more complex than the terminology “old” and “new” regimes implies. Old regimes of practice are less hegemonic than the depictions of them by 1970s women’s health scholars. The narratives of feminist health scholarship, telling stories about this regime of practices, helped launch a new kind of women’s health movement seeking to unseat sovereign physicians. At the same time, old regimes of practice have not completely disappeared today, although they have been generally displaced by new regimes of practices.⁵

Foucault proposed the concept of discourse that can help us make sense of these two forms of power. He argues, “There is not, on the one side, a discourse of power, and opposite it, another discourse that runs counter to it. Discourses are tactical elements or blocks operating in the field of force relations; there can exist different and even contradictory discourses within the same strategy; they can, on the contrary, circulate without changing their form from one strategy to another, opposing strategy” (Foucault 1978, 101–102). The stories of DES daughters herein show that old and new regimes of power guided the work of medicine and science in working out solutions to problems experienced by DES daughters from the 1970s to the present. This book is unique in its exploration of old and new regimes of practice, interpretation of narratives in different settings, and analysis of how different ways of telling DES stories provide clues to an embodied health movement.

Embodied Health Movements

Embodied health movements are among the innumerable points of power in regimes of DES practices. Beginning with women’s health movements of the late 1960s, there are now many embodied health movements, concerning for example HIV/AIDS, breast cancer, childhood asthma, and DES. From among a large, growing, and increasingly complex arena of patient groups and health movements, “embodied health movements” are distinguished by framing their organizing efforts and critiques of the system through personal

awareness and understanding of individuals' experiences and by challenging science—from forming alliances with scientists to secure funding and legislation to collaborating in the “doing” of science (Brown et al. 2004; Epstein 1996, 2008). In fact, many embodied health movement activists become involved in response to a direct experience of illness, and their everyday realities living in and through their bodies continue to seep into their activist work (Klawiter 2003; Bell 1988).⁶ Embodied health movements also challenge aspects of the political economy and transform traditional assumptions and lines of inquiry regarding disease causation and strategies for prevention (Brown and Zavestoski 2004, 682). These movements have become important sources of change in health care as well as major forces advocating change beyond health care by posing “collective challenges to medical policy and political belief systems, research and practice [and they] include an array of formal and informal organizations, supporters, networks of co-operation, and media” based on lived experiences (Brown et al. 2004, 52). The politicized collective work of embodied health movements transforms illness experiences, critiques medicine's treatment of patients, and turns attention away from individual bodies as sites of risk to the risky environments in which the patients live (Brown et al. 2004, 51).

Science is an “inextricable part” of embodied health movements (Epstein 1996). Activists challenge professional expertise, expand the meaning of “expertise,” and become a new species of expert (Epstein 2000). But rather than dismissing formal knowledge altogether, a key strategy of embodied health movement activists is gaining a place at the scientific table and drawing from their personal illness experiences—as well as from their acquired scientific credibility—while sitting there (Brown et al. 2004; Epstein 2000). Many groups combine experiential knowledge with “varying degrees of mastery of formal knowledge” in hybrid ways of knowing (Epstein 2008, 518).⁷ Activists' participation at the scientific table can consist of reviewing and evaluating the methodologies, ethics, and topics of proposed clinical trials for federal funding by the National Institutes of Health (NIH) or Institutional Review Boards and acting as informal representatives to committees advising the Food and Drug Administration in the evaluation of new drugs (Epstein 2000). Becoming research collaborators and coauthors, attending or being on the program of scientific conferences or meetings, and establishing new models for participatory research are other ways that embodied health movement activists have reconfigured the knowledge-making practices of biomedicine (Bell 2003; Epstein 2008). Yet by expanding the possible points of entry into knowledge-making, this reconfiguration also transforms the worldviews and dynamics of power among activists themselves (Brown et al. 2004; Epstein 1996). For example, hierarchies within embodied health movements have

emerged between those activists who have and have not “sat at tables,” or between activists who have become familiar with “scientific and technical knowledge or tools” and others who have not (Epstein 2008, 518). “Expertification” and “scientization” among activists also create barriers to the entry of potential new members (Epstein 2000, 2008).

To a large extent, embodied health movement activists must depend upon scientific understanding and innovation for long-term screening and treatment (Brown et al. 2004, 56). There are multiple pathways and consequences of this dependence. Over time, embodied health movement activists participate in regimes of practice, entering at multiple points, seeing a variety of practitioners, and undergoing a range of treatments. Being subjected to these repeated and diverse encounters with continuously transforming practices and practitioners reshapes their subjectivities. The need for long-term screening and treatment also fosters faith in the scientific establishment. Even when their tactics are confrontational, embodied health activists resist the notion that the scientific establishment is “the enemy.”⁸ Their dependency and strategic interventions produce knowledge, habits, and discourses, contributing to constant modifications and continual shifts in regimes of science. At the same time, the incorporation of expert knowledge transforms the subjectivities of embodied health activists with biomedically informed changes in their understandings and experiences of their own bodies. DES activism is one of many embodied health movements that draws from lived experiences to construct a politicized collective, to engage in consciousness raising and identity work, to critique science, and to continually return for screening and a variety of medical interventions.

There is no simple story or truth about how embodied health movements work, because no two of them are exactly alike. Each has its own set of issues, participants, and so forth. Indeed, these multistranded and diffuse movements might best be conceived of as coalitions or loosely connected sets of activities rather than consciously structured organizations, because they encompass such a wide range of groups and service providers, interests, and manifold projects (Epstein 2000; Klawiter 2003). Embodied health movements exceed the usual boundaries of social movement activity in fractured unities and regroupings, so that the “actions of state officials, scientists, and others who might not typically be thought of as within a movement, can be understood in light of the culture of action in which the movement takes place” (Brown et al. 2004, 64). Instead of seeming to be a singular concept, the multifaceted nature of embodied health movements opens them up to be studied in a nonlinear, nonpositivistic way. In fact, their very hybridity lends itself to a narrative understanding of them. In the next section, I show how the epistemology and methodology of narrative analysis emphasize multiplic-

ity, fluidity, and reflexivity, approaches to understanding social life that can make sense of these hybrid social movements and of the multistranded DES embodied health movement. Approaching DES narratively does not produce a simple or “one true” story of this embodied health movement, because there is not “a” story to be told.

Narrative Analysis and DES Stories

This book contains the story of an embodied health movement and the stories of individuals producing, participating within, affected by, and circulating through this movement. Central to the book are the stories of DES daughters. These stories are drawn from interviews; “Letters to the Editor” and “Personal Accounts” published in the DES Action newsletter, *DES Action Voice* (1979–2001); an autobiographical film, *A Healthy Baby Girl* (Helfand 1996); and narrative accounts produced during a scientific conference, “1992 NIH Workshop: Long-Term Effects of Exposure to Diethylstilbestrol (DES).” Together, these different ways of telling and showing DES stories provide clues to how individually and collectively DES daughters drew from cultural resources to create an embodied health movement that engages critically with the “old” and “new” regimes of DES.

The core evidence is personal narratives from in-depth interviews with twenty DES daughters, ten who had had DES-related cancer and ten who had not, that I conducted from 1982 to 1995. The women were between ages twenty-one and forty when they were interviewed.⁹ The interview design encouraged them to manage the direction and pace of the interview. Although I did not ask them to tell stories, they often answered my questions by telling stories; indeed, a careful look at the discourse demonstrates that the two of us constructed stories in the space between us.¹⁰ The stories—personal narratives—that emerged during these interviews include rich and complex clues about the ways individual DES daughters have understood and engaged with medicine since the late 1960s.

In interviews, published accounts, the 1992 DES Workshop, and film, the construction of the DES daughters’ stories, like the events that they portrayed, took place in specific historical contexts and shifting relations of power. Their stories are not simply representations or explanations of events that took place in their lives or reports of feelings that these events evoked, but indications of the settings in which they were produced and the regimes of practice in which they were “lived.” For example, even when describing “what might appear to be ‘just personal’ details,” DES daughters, like other people, “locate themselves politically, economically, and historically” (Andrews 2002, 11). They inevitably weave dominant discourses of a social insti-

tution—such as medicine—into personal narratives about lived experiences with the institution. Yet, despite the power of dominant discourses, people “interpret past experiences in composing lives in the present that adapt to, resist, and sometimes reach beyond” them (Riessman 2002, 37). Speakers can “dip in and out of dominant cultural scripts . . . manipulating and reformulating them in ways that are not always immediately apparent. The end result is an unanticipated and very subtle subversion” of the dominant cultural script (Andrews 2002, 9). DES daughters’ stories alternately reflect, resist, or transform dominant discourses about expertise, disease, gender, and power.

Placing DES daughters’ stories at the center of this book connects my analysis to the narrative turn in social sciences and extends that turn by incorporating the production of multiple narratives in multiple locations. In its reflexivity, the narrative turn is one response to disenchantment with the “dominant ‘Cartesian’ paradigm of rationality” at the core of modern social science (Hinchman and Hinchman 1997, xiv). Narrative approaches counter traditional models of knowledge by stressing that there are multiple truths, constructed by knowers who are socially and historically located, about a world that is neither fixed nor independent of knowers. At the same time, narratives do not have fixed meanings. They are produced collaboratively and can be interpreted differently by different audiences. And, as collaborative performances, narratives connect selves to one another—tellers with listeners, writers with readers, performers with audiences, photographers with viewers, narrators with present or imagined others (Langellier 2001a, 700; see also Bell 2002). The turn to narrative attends to the narratives of informants and interviewers’ participation in the construction of *their* stories and also to the ways in which their stories become interpreted and retold as *our* stories.

Building on the canonical work of William Labov and Joshua Waletzky (1967), I define “narrative” as a sequence of ordered events that are connected in a meaningful way for a particular audience in order to make sense of the world or people’s experiences in it (Hinchman and Hinchman 1997). This definition assumes one action is consequential for the next, that a narrative’s sequence is held together with a “plot,” and that the “plot” is organized temporally or spatially (Riessman 2002, 698). More than a list or a chronicle, a narrative adds up to “something.” In constructing a narrative, people make single events meaningful in relationship to other events, especially when events do not obviously make sense, “where there has been a breach between the ideal and real, self and society” (Riessman 1993, 3). When a person’s life is interrupted by an illness, narrative offers “an opportunity to knit together the split ends of time, to construct a new context,” and to fit the disruption caused by illness “into a temporal framework” (Hydén 1997, 53). Narrative analysis displays how this “something” emerges by taking the story itself as

its “object of investigation” (Riessman 2002, 696; Bell 1988).¹¹ The details of talk—how stories are put together, the images, pictures, and explanations interwoven in them, and the position of narrator in relation to the story events and audience—all convey something important about a narrative’s meanings. Whereas most narrative research inspired by Labov and Waletzky focuses on the “discrete story as the unit of analysis” (Riessman 2002, 698), multiple narratives are produced interactionally during interviews, in written exchanges, and in other settings. Tracing the details of multiple narratives in different contexts—for example within and across interviews, in letters to the editor, and during a scientific conference—displays DES daughters’ accumulated knowledge and experiences of their bodies and reveals their participation in old and new regimes of DES.

The particular context in which narratives are produced “matters” for their production and interpretation (Polletta 2006). Until recently, most social science scholarship focused on the production and interpretation of narratives in face-to-face research interviews (Riessman 1993, 2008). As they have expanded the scope of narrative inquiry, scholars have focused on narratives in different contexts. One of these is letters to the editor in newsletters, magazines, newspapers, and Web sites. Like other narratives, letters are social practices, drawing writers and readers together in an exchange, and have structural conventions (address, salutation, business, farewell, and signature) that help shape their content (Jolly and Stanley 2005). Relationships and cultural discourses are reflected and constructed in “the performative, textual, and rhetorical aspects of letters” (Stanley 2004, 211). Writing letters in response to reading feminist texts was an important dimension in the development of feminist ideas and communities during the 1970s and 1980s, particularly for women’s health activism (Kline 2005; Davis 2007). Together, letter writers developed a “virtual community of health feminists” (Kline 2005, 89).¹² Particular exchanges or bodies of letters written by individual writers to different sorts of correspondents are socially and historically located, have shapes—“temporal dimensions, elisions, and silences, gaps and destructions and interpretational framing”—and discursive strategies (Jolly and Stanley 2005, 84–85). When editors bring letters together, publish them, and contextualize them—as do the editors of the *DES Action Voice*—they act as “brokers” between writers and readers, interpreting and filtering knowledges (Jolly and Stanley 2005, 93).

Another context is in public discourse. Feminists have long noted women’s exclusion from public discourse. Although this “has never in practice been absolute, and women in many societies past and present have found ways to make their voices heard, there does seem to be a relatively widespread and long-lived pattern whereby the public contexts that have most symbolic

value are also the most resistant to the equal participation of women” (Cameron 2006, 8–9). Recent scholarship has considered how public speech is produced and negotiated in different local settings and communities of practice, and the extent to which “alternative discursive practices” can be implemented (Baxter 2006, xviii). At the 1992 DES Workshop, women in different locations found ways to make their voices heard. The “small stories” (Bamberg 2006) and personal narratives produced during the 1992 DES Workshop came from everywhere—from women and men panelists, audiences, DES activists, biomedical scientists—and destabilized the discourse of science as usual. They blurred the boundaries between what constitutes “science/not-science” and “scientist/not-scientist” and exemplified as well as opened up space for a DES embodied health movement.

Visual narratives, produced for public consumption, are also crucial points in the DES embodied health movement. DES daughters created films (Helfand 1996; Helfand and Gold 2002), plays (Picoult 1991), and photo essays (Braun 2001) to make visible and to give voice to their experiences, to challenge existing medical and scientific knowledge about DES, and to reconfigure the political landscape.¹³ Many different kinds of visual evidence have been employed by social scientists on and off for over a century, including maps, drawings, diagrams, plans, tables and charts, films, paintings, and photographs (Harrison 2002). Narrative scholars began doing so only recently.¹⁴ The autobiographical documentary film *A Healthy Baby Girl* shows and tells DES stories by weaving together everyday events filmed by Judith Helfand during a five-year period with photographs, interviews, entries from a journal of drawings Helfand created after her surgery for DES cancer, and archival footage from the 1940s and 1950s. *A Healthy Baby Girl* is located within a genre of film documentaries that began to appear in the 1960s, when (ethnographic and documentary) filmmakers began to put themselves into their films.¹⁵ Like other autobiographical documentaries, *A Healthy Baby Girl* includes reflexive strategies that contest objectivity, distance, and the noninterventionism of traditional documentarians; incorporates the filmmaker as a character in the story; shares textual authority by handing over the camera; and renders the private sphere a matter for public knowledge (Renov 1999; Lane 2002). As does the turn to narrative in the social sciences, the turn to autobiographical documentary responds to disenchantment with the dominant paradigm of “historical and scientific objectivity” (Lane 2002, 5). In an autobiographical documentary, “there is no fully outside position available” (Renov 1999, 142). The multilayered display of sounds and images in *A Healthy Baby Girl* underscores messages some sociologists have claimed for textual narratives—of their open, shifting, and multiple meanings, the importance of the audience in producing

and interpreting them, and ways in which they can reshape and reform dominant cultural scripts.

Narrative analysis enables the possibility of seeing how change comes about. By employing narrative analysis, and thus placing DES daughter stories at the center of the book, I show how individual lives are connected to social structure. DES daughters' stories have the potential for forging links between DES daughters and providing support to each other as well as connecting the personal experiences of individuals to public issues of social structure, thereby creating and sustaining embodied health movements.

When individual people make choices and decisions about their lives (responding to the diagnosis of cancer or attempting to become mothers, for example), they simultaneously make sense by drawing from dominant discourses and creatively rework, reconfigure, or resist them, drawing from what is at hand, creating new pathways through old narratives and new cultural scripts. Together, the DES stories produced in interviews, letters to the editor, a scientific workshop, and visual materials show old and new regimes of practice in a DES embodied health movement.

Plan of the Book

Employing the frameworks of narrative analysis, embodied health movements, and feminist health scholarship, the chapters take up, in succession, DES history, politics of knowing, becoming mothers, remapping bodies, and producing change. Chapter 1 sets the context for understanding the stories of DES daughters and postmodern feminist health scholarship and activism with an embodied history of DES. It begins with the early history of DES, the hormonalization of women, and women's responses from the synthesis of DES in 1938 to the discovery of its carcinogenic effects in DES daughters in 1971. It traces the emergence of the DES embodied health movement in an institutionalized field of knowledge, practice, and power forged by medical scientists and DES activists for the next twenty years, leading up to and providing the possibility of successfully organizing the 1992 DES Workshop. It concludes by summarizing the multiple strands of activism and regimes of practice emanating from the 1992 workshop and their review at the 1999 DES Research Update Workshop.

Chapter 2 explores how knowledge about DES is produced, how doctors and daughters exercise power in the production of knowledge, and ways in which the field of power and knowledge has been transformed from the late 1960s to the 1990s. This chapter focuses on the experiences of DES daughters who had cancer, how they learned of their exposure to DES and DES cancer, how they assumed the identity of "DES daughter," and how their assumption

of this identity and their negotiations with their physicians participated in the construction (and transformation) of medical knowledge about DES. It begins with a story by a DES daughter (“Esther”) who developed cancer before the link between prenatal exposure to DES and vaginal cancer had been identified, before the name “DES daughter” had been given to women exposed to DES prenatally, at a time when vaginal cancer in premenopausal women was almost unprecedented, and before there was a women’s health movement. Her story exemplifies an “old regime” of practices. Stories of women who developed cancer in the 1980s demonstrate how “new regimes” of practice work, when doctors were no longer granted authority by the institution of medicine in quite the same way, and patients were no longer passive victims of that institutionalized authority.

In Chapter 3, old and new regimes of practice appear in a different arena—the cultural imperative to become mothers—from the early 1970s to the present. This chapter focuses primarily on the experiences of DES daughters who have not had cancer, who worried in anticipation of attempting to become pregnant, whose difficulties led them more and more deeply into the use of new reproductive technologies, and who suffered from multiple pregnancy losses. It looks critically at discourses of mothering that presume motherhood is a goal for all women and that the progression from desire to healthy baby is seamless. It interweaves interview narratives with “Personal Accounts” and “Letters to the Editor” in *DES Action Voice*. The chapter begins with a letter sent to *DES Action Voice* by a DES daughter in the early 1980s. “Stacey” tells a story of her harrowing experiences becoming a mother. She was deeply invested in satisfying the cultural imperative of motherhood and had multiple medical interventions and pregnancy losses before the premature birth of her daughter. For DES daughters, becoming a mother is fraught with fear and uncertainty, simultaneously difficult as a result of their bodies’ responses to prenatal exposure to DES and challenging in their re-entry to systems of medical surveillance recommended and often required for the successful production of children. DES daughters have to negotiate the promise offered by new reproductive technologies with the failure of the earlier promise of DES, and in this negotiation based on their lived experiences they gain the authoritative voice to produce knowledge, to inform, and to contest the medical view. This contest and negotiation is demonstrated with DES daughter stories from the 1980s and 1990s about becoming and not becoming mothers.

DES daughters have, by their definition and medicine’s definition, medically deviant and socially non-normative bodies. Chapter 4 begins with a story of medical heroism, in which medicine had the authority, the knowledge, and the power to reconstruct the body and thus made DES daughters’

bodies less medically deviant but not always more normatively functional. It analyzes the interview narrative of a DES daughter (“Cassie”) who had cancer in the late 1960s, telling of medical heroism to save her ability to have sexual intercourse by reconstructing her vagina as well as the limits of medicine in this respect. Stories from the 1980s show how these medical limits created possibilities for DES daughters to speak authoritatively about their bodies and to talk back to medicine in “‘local centers’ of power-knowledge” (Foucault 1978, 98). In their production of knowledge about the way their reconstructed bodies are still not normatively functional and cannot be made functionally whole, DES daughters contested medical sovereignty and the view that medicine can fix everything and anything. In its demonstration of medicine’s limits, Chapter 4 complements Chapter 3, in which physicians’ skills go a long way to accomplish the cultural imperative of motherhood.

Chapter 5 widens the discussion, looking at daughters, doctors, and scientists—historically a hierarchy of knowledge and power from scientists at the top to daughters at the bottom—and tracing the dynamics of an embodied health movement by focusing on stories from the 1990s. The chapter begins with the opening of the NIH-sponsored 1992 DES Workshop and shows how power is “exercised from innumerable points, in the interplay of nonegalitarian and mobile relations” (Foucault 1978, 94). Subjugated knowledges—those forms of knowledge that are considered naïve, not scientific, or inadequately scientific—and authoritative knowledges circulate among the participants. Although the discourses of new regimes are dominant, those of old regimes also guide the work of medicine and science in working out solutions to problems experienced by DES daughters. By analyzing stories told during the 1992 DES Workshop from the podium and the audience as well as works of art about DES performed off the workshop floor, it shows how doctors, daughters, and scientists make multiple forms of knowledges—sometimes collaboratively—and have multiple and shifting voices in the production of knowledge.

Chapter 6 interprets narratives in the autobiographical documentary film *A Healthy Baby Girl* by DES daughter Judith Helfand (1996), about her experiences from 1990 (when she was diagnosed with cancer) until 1995 (the fifth anniversary of her surgery). The significant impact of DES is introduced through Helfand’s film, which explores cultural assumptions about gender, ambiguity and uncertainty in medical knowledge, and the necessity of drawing from and reworking available resources to recover from DES cancer. The film also tells a story of old and new regimes of practice in medicine and science and of the DES embodied health movement—of multifaceted and hybrid activism that draws from and continually returns to the lived experiences of DES daughters. In the first narrative—the opening scenes

of the film—Helfand draws connections between her life and the political, economic, medical, and scientific worlds of DES. In the second narrative, Helfand and her parents talk about infertility, assisted reproduction, and the possible effects of DES on Helfand's eggs. Embedded in the "eggs" narrative is a shared insight about the significance of DES in the formulation of the endocrine disruptor hypothesis: that chemicals can cross the placenta, disrupt the development of the fetus, and have effects that might not appear until decades after a baby's birth (Colborn, Dumanoski, and Myers 1996–1997). This hypothesis widens the focus from cancer and acute toxicity to reproductive and developmental damage. A third narrative shows and tells a story of Helfand's mother and father sending letters to President George H. W. Bush, urging him to sign the DES Research and Education Bill—passed by the U.S. House and Senate in 1992—into law. The "Dear President Bush" story re-introduces letters as social practices and explores these letters to the president as examples of a well-established strategy of public discourse and activism in American politics.

The Conclusion begins with a description of a DES Action thirtieth-anniversary celebration in September 2008, reflects on the future of the DES embodied health movement, and looks ahead to the future of embodied health movements, narrative scholarship, and transformed relationships of power and knowledge in women's health politics.

In sum, this book weaves together different narrative strands over time and across space to explore how illness, suffering, and uncertainty can become opportunities for producing embodied knowledges and making social change.