

‘Breast Cancer on Long Island’: The Emergence of a New Object Through Mapping Practices

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Abstract

In late 1980s and early 1990s ‘breast cancer on Long Island’ emerged as a distinct object characterized by higher than average incidence rates that some speculated could be explained by environmental factors. The scientific community and its discourses have played an authoritative role in delimiting what is officially ‘known’ and ‘not known’ about this specific disease ontology. This article moves beyond an epistemological focus towards what Annemarie Mol calls a ‘praxiographical’ inquiry into the everyday practices that produce complex disease objects. We consider how multiple and multi-sited practices of mapping breast cancer on Long Island—by activists, scientists and the state—contributed to the emergence of this new object, and to its multiple and shifting enactments over time. We explore the tensions and power relations between the ‘lay’ public and scientific ‘experts’, and how these influenced mapping practices and produced ‘breast cancer on Long Island’ as a complex and ongoing politico-scientific event.

Keywords activism, breast cancer, Long Island, mapping, praxiography, science studies

What is ‘breast cancer on Long Island’? How do we address the problem of a particular disease in a particular place? Many people’s first response to these questions would likely be: ‘What does science say it is? And, what does science propose we do to address this problem?’ In this article we think through some of the methodological and conceptual challenges that science studies perspectives can pose to this common-sense privileging of science as authoritative do-er, knower and, in many senses, producer of disease ontologies. Although science has played a pivotal role in determining what ‘breast cancer on Long Island’ is, and what it isn’t, over the past two decades, it has not been alone in this enterprise. Recent work in science studies provides a method for moving beyond an epistemological inquiry altogether towards what Annemarie Mol (2002: 32) calls a ‘praxiographical’

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inquiry into the everyday practices that produce a complex object like ‘breast cancer on Long Island’. Through this kind of analysis, ‘knowing’ (whether by scientist knowers, doctor knowers, patient knowers, activist knowers, etc.) might be understood as just one practice among many that converge to produce what is ultimately a complex and changing object. ‘Breast cancer on Long Island’ emerged at a particular point in time (in the late 1980s and early 1990s) because of a confluence of very specific practices, including but not limited to scientific, medical, environmental, media, activist and political ones. Over time many different practices, or enactments, have made, unmade, and remade this object. In this essay we focus on the multiple practices of ‘mapping’ breast cancer that have played such a prominent role in making ‘breast cancer on Long Island’ both a political and scientific, or politico-scientific, event. In our analysis, a map doesn’t simply demarcate a place; rather, various practices of mapping make subjects, objects, and places. We explore these practices of mapping not simply as spatial practices, but also as temporal ones, concerned with rendering a particular present in relation to the past and also, sometimes, in relation to a future.

We began our larger project¹ by looking for the first signs of a problem. In this case, such signs were not difficult to find: from the mid-1980s various reports suggested that the incidence of breast cancer on Long Island was higher than ‘normal’.² Once these early warning signs became public, citizens and politicians demanded that the New York State Cancer Registry be updated in order to determine whether signs of higher incidence were based on ‘scientific fact’, some statistical anomaly or fear-induced conjecture.³ What

1 The larger project is a digital video archive of interviews with people with breast cancer on Long Island, breast cancer activists, health practitioners who care for people with breast cancer, scientists studying breast cancer, and New York State and county public health officials and politicians, all of whom we take to be integral to the emergence of ‘breast cancer on Long Island’. Before we began the digital video archive, we felt we needed to first carry out a thorough review of news reports and scientific publications regarding the event of breast cancer on Long Island. This article is an analysis of just one of the prominent practices—mapping—that we have discerned from that review. We have not yet begun the formal interview process for the digital video archive.

2 Statistics on breast cancer incidence on Long Island are most often derived from the New York State Cancer Registry coordinated by the New York State Department of Health (NYSDH). The Registry contains all reports from doctors and hospitals of new cancer diagnoses as well as deaths. These data are then made into statistics for the various cancer types, and are presented in a series of publicly accessible tables, showing breast cancer rates for each five-year period from 1976 on (the most recent data goes up to 2002). Tables exist for all of New York State, just New York City, New York State excluding New York City, and each county in the State (including Suffolk and Nassau, the two Long Island counties). See NYSDH (2005a, 2005b), both available at www.health.state.ny.nysdoh/cancer/nyscr/vol3.html

3 Locating the precise point in time that practices of breast cancer on Long Island became ‘activist’ and ‘political’ is difficult. Organizations were mobilized in the early 1980s to provide support and information about breast cancer, and to raise awareness about early detection among women. It is likely that these forums provided a space for women to become critically conscious of the political and collective dimensions of the disease. However, the consensus on activist websites, and in news reports, is that ‘breast cancer activism’, as a category of practice separate and qualitatively different from existing support and educational activities, emerged during the late 1980s and early 1990s. From the beginning, as we will show in more detail below, this ‘breast cancer activism’ was conceived specifically in relation to issues of science and research. The emergence of activist groups was, according to activists and the media, primarily a response to a specific scientific inquiry into the problematic rate of breast cancer on the Island—the Long Island Breast Cancer Study (LIBCS), which was initiated by the State of New York in 1985. News articles covering the progress of the LIBCS between 1985 and 1990 (when it was first announced as ‘concluded’ by health officials) consistently cite incidence data from the New York State Cancer Registry, which indicated that, between 1978 and 1982, the incidence rate for breast cancer for Nassau County, the western part of the island, was 12 percent above the statewide rate and 7.5 percent above the nationwide rate, while the incidence rate for Suffolk County, the eastern part of the island, was just slightly higher than average. For early reports on breast cancer incidence on Long Island, see Baldwin (1985), Tusiani (1988) and Slatella (1988). The LIBCS was initiated by health scientists in government, without any public prodding to do so. The results of this study then catalyzed many new practices, and created significantly different motivations for organizing

followed from this discovery of a problem was the emergence of practices of breast cancer activism, as ordinary citizens attempted to gather evidence about the problem by mapping breast cancer incidence in their own communities. These citizen mapping practices brought many middle-class, mostly white, suburban women into the public spaces of politics and science, spaces which had been previously unfamiliar, or even inhospitable, to them. These mapping practices also created a nascent social movement that would become an integral player in pressuring the scientific community to conduct studies into the possible links between the environment of Long Island and breast cancer. This pressure would lead to the enactment (literally into Public Law 103-43) of the Long Island Breast Cancer Study Project (LIBCSP) in 1993, which dictated that scientific studies be conducted to determine if and how Long Island's environment was causing this higher incidence of breast cancer. Public Law 103-43 dictated not only that studies should be done, but that they should be done using particular scientific methods.⁴ Many of the studies that were conducted as a part of the LIBCSP were published in 2002, and both scientists and activists agree that these studies failed to demonstrate any significant link between the environment and breast cancer.⁵

We are interested in the particular reasons (both political and scientific) for the failed studies, and also in the ways that this moment signals an instance of the failure of the object—'breast cancer on Long Island'—to cohere. What do activists and scientists do with these failed studies and this failed object?⁶ One practice that they turn to again is mapping, and in this instance it is a form of mapping that both returns to and transforms the earlier citizen mapping practices that helped bring 'breast cancer on Long Island' into being in the first place. By exploring the multiple practices that have brought 'breast cancer on Long Island' into being, and have also, paradoxically, covered over this object, we hope to demonstrate the complex relationships between a particular disease and a particular place and time.

Complexity and cancer

In a recent article in the *New York Times*, theoretical physicist Lisa Randall discusses why the general public often misunderstands the nature of scientific developments. Randall begins by noting that the lay definition of 'theory' is quite different from the way scientists

around breast cancer. For an account of emerging politicization in response to the LIBCS, see Swirsky (2005). Swirsky began writing about breast cancer on Long Island in 1985 for the *Women's Record*, and for 20 years has been a health and science features writer for the *New York Times* Long Island Section. The West Islip Breast Cancer Coalition (WIBCC), discussed below, calls her 'our breast cancer historian on Long Island'.

4 In particular, Public Law 103-43 specified that scientists should do case-control studies into possible associations between breast cancer and specific environmental factors. By the time the studies were published, many scientists were already arguing that the case-control design of the original studies was a mistake, and that longitudinal studies would have provided better data.

5 Studies published in 2002 include Gammon *et al.* (2002a, 2002b, 2002c). Other studies were published in 2003, including O'Leary (2003) and Kabat (2003).

6 One of the reviewers of an earlier version of this article expressed discomfort with what s/he read as the 'unproblematized' way in which we refer to the LIBCSP studies as 'failed studies'. We use this terminology because this is the terminology that both scientists and activists used in regard to these studies. However, we do indeed want to problematize this perception, though not by suggesting these studies didn't fail. Rather, we want to suggest, and even revalue, failure as a necessary and potentially creative component of both scientific and political practices. For a discussion of an 'ethics of failure' in relation to practices of medicine, see Diedrich (2007), especially the conclusion entitled 'Toward an Ethics of Failure'.

use the term. Randall says that most people use the word ‘theory’ loosely to ‘describe a passing conjecture that they often regard as suspect, [while] physicists have very specific ideas in mind when they talk about theories’ (2005: 13). ‘For physicists’, Randall writes, ‘theories entail a definite framework embodied in a set of fundamental assumptions about the world that lead to a specific set of equations and predictions—ones that are borne out by successful predictions’ (2005: 13). The most important aspect of Randall’s definition, for us, is a temporal one. She reminds us that, ‘theories aren’t necessarily shown to be correct or complete immediately’ (2005: 13). Theories emerge at a particular time and in a particular space, and often change over time and as they travel between domains. To highlight the temporal aspect of all theory, Randall briefly mentions evolutionary theory and the challenge to it from advocates of ‘intelligent design’. She says, as ‘intelligent design’ advocates do too, that ‘evolution is by no means a complete theory’ (2005: 13). Simply put, there are gaps in our knowledge of how evolution works. But, unlike intelligent design advocates, Randall understands that these gaps are ‘incentives for questions’; they are reasons to do further scientific study that, it is hoped, will better describe the complexity of the processes and structures of evolution, or indeed, of the processes and structures of the natural world more generally. ‘Most [scientific] developments reflect work in progress’, Randall notes, again emphasizing the temporality of science, ‘so the story is complex because no one yet knows the big picture’ (2005: 13).

So, how to begin to capture the, or a, big picture of a complex object like breast cancer on Long Island? We have adopted a method that is concerned less with how we know this object and more with how it gets enacted in practices. Like Annemarie Mol’s ethnographic study of the multiple object ‘atherosclerosis’ as it is enacted at a teaching hospital in a Dutch town, we are interested in shifting ‘from an epistemological to a praxiographic inquiry into reality’ (Mol, 2002: 32). Mol situates her praxiographic approach in relation to a longer tradition in social theory and science studies that focuses on practices. In Mol’s own genealogy of the method of inquiry of which her work is just one strand, she traces back from more contemporary work on actor-network theory⁷ to Goffman’s important early theorization of performativity in *The presentation of self in everyday life* (1959). Mol rejects the term ‘performance’ in favor of a term that she argues is ‘still relatively innocent’ (2002: 41).⁸ That more innocent term, for Mol, is ‘enact’. In Mol’s analysis of the enactment of atherosclerosis, there is not one atherosclerosis, but many atheroscleroses, which isn’t to say that the multiplicity of this or any object means it fragments into countless tiny pieces. The multiple object ‘atherosclerosis’, in the Dutch teaching hospital and beyond it, does somehow manage to cohere, so that you know something of what we mean when we use the term. Still, by approaching objects as multiple, we can begin to look at them anew; we can study how they come into being, change, disappear and reappear.

7 John Law, one of Mol’s main collaborators, is also one of the key theorists of actor-network theory. He describes actor-network theory as a ‘semiotics of materiality’, which understands all objects (not only linguistic entities) as always produced in relation to other objects (see Law, 1999: 4). Projects utilizing this theory explore the complexity of objects and how they come into being in relation to other objects. For work influenced by actor-network theory, see, for example, Law (2002) and Mol and Law (2002).

8 Although Mol acknowledges that she has used the term ‘performance’ in previous work, in *The body multiple* (2002), she distances herself from performativity studies that can be traced back to J.L. Austin’s speech act theory. She seems concerned to expand her domain of analysis beyond practices that are solely or primarily linguistic.

In *The body multiple* (2002), Mol explores the ontology of a multiple object through the practices that make it. To do this, she intentionally chooses an object that is, at least on first glance, uncontroversial or apolitical. Atherosclerosis in the leg is not a disease that is particularly moralized, nor has there been much if any activism calling for better treatments by and for people with atherosclerosis in the leg. Mol wants to demonstrate her method, which she calls empirical philosophy, on an object that appears almost banal. But she also makes it clear that she wants her method to be appropriated by others looking at objects that are less banal, and, even, decidedly political. Our work on 'breast cancer on Long Island' appropriates Mol's method, and does so to look at an object that from its beginning was enacted through political as well as scientific practices, and certain practices, like mapping, that bring these two domains together.

We also want to briefly mention another important science studies text that informs our approach here: Steven Epstein's *Impure science* (1998), which describes the science and activism surrounding both causation of and treatment for HIV and AIDS. Epstein shows that while AIDS activists were successful in becoming important players—experts even—in the field of treatment, in terms of the way drug trials were conducted and how new drugs were released to the public, they were not successful in becoming experts on causation. Epstein analyzes the way that HIV became the hegemonic scientific explanation for AIDS, despite continued and persistent attempts to challenge HIV as the cause of AIDS. When activists would occasionally weigh in on these AIDS causation controversies, scientists largely ignored them. We don't have the space here to rehearse Epstein's brilliant delineation of the AIDS causation controversy, but we mention his analysis to suggest that breast cancer activism on Long Island has been different from AIDS activism in at least one important respect: breast cancer activists on Long Island were most interested in working with scientists to determine the causes of breast cancer, not to develop better treatments.⁹ This is a crucial difference between AIDS activism and the breast cancer activism on Long Island because, as Epstein demonstrates, scientists are often able to grasp—intellectually and/or intuitively—the need for input from people with a particular disease into the treatments for that disease, while research into cause is 'pure science', which most scientists believe will not benefit from the intrusion of non-experts.¹⁰ The very notion that research into cause is 'pure science' is itself challenged by breast cancer activism on Long Island, which, in the beginning at least, pushed for epidemiological studies into environmental causation rather than the 'purer' studies into genetic causation.¹¹ Combining Mol's praxiographic

9 There are other differences between AIDS activism and breast cancer activism. In an article entitled 'The anguished politics of breast cancer', and subtitled 'Taking their cue from AIDS activists, a growing army of survivors press angrily for more money, more research—and more respect', Susan Ferraro discusses some of the differences between the two movements. The women she interviews are portrayed as unlikely activists—an 'odd sort of army'—who show *surprising* political savvy. In contrast to AIDS activists, they are, Ferraro maintains, '(so far) less confrontational', though she does mention WHAM (Women's Health Action and Mobilization) member Matuschka, who 'makes art of her mastectomy with poster-size, one-breasted self-portraits that force people to see what cancer does' (1993: 27, 58). More often though, according to Ferraro, these unlikely activists opt for coalition-building strategies and lobbying to influence those in government or the medical profession whose support might be beneficial to breast cancer survivors.

10 According to Epstein, the difference in the domains of causation and treatment is between 'a more insulated preserve of biomedicine' and 'a more public and 'applied' domain' (1998: 337).

11 We thank the reviewer who pointed this out to us. S/he noted that the causation research that activists sought was 'impure (and literally quite dirty) research, in so far as it includes collecting soil, dust, etc. samples from women's homes and living environments'.

approach with Epstein's analysis of the self-fashioning of experts in the face of disease ontologies that are not fully known, we also investigate in this article the making and remaking of breast cancer activists.

Turning to science

Breast cancer activism on Long Island—its emergence and enactments over time and space—is most notably a story of science.¹² Media coverage between 1985 and 2005 indicates this clearly.¹³ Virtually every article that mentions activism around breast cancer refers to some aspect of the relationship of this activism to science, whether through practices associated with activists' central demand for more scientific research on the environment and prevention, through their own local and 'non-expert' research activities, through their enlistment of scientists in these activities, or through their steadfast insistence on their inclusion in research, not just as subjects of studies but as experts on the experience and event of breast cancer on Long Island. Media coverage reveals how activists' engagement with science is complex and multi-layered, and often contradictory. On the one hand, by entering domains from which they had previously been excluded, breast cancer activists on Long Island might be said to have posed an effective challenge to the authority of science, and even to the 'rules of the game' of the scientific establishment. On the other hand, because they wanted, and felt they needed, science to legitimate their own forms of expert knowledge, their challenge to how science is practiced, and by whom, only went so far. In the end, the over-reliance of activists on science seems to have been to their disadvantage, especially when scientific studies failed to legitimate their long-held claims about environmental causes of breast cancer. The failure of science to legitimate the claims of activists reveals the dangers of a strategy wholly dependent upon scientific research and its authority. In our conclusion, we will argue for an approach that acknowledges the current limitations of science to study the relationship between cancer and the environment, but nonetheless does not reject the possibility that future research will be better able to understand the complexity of this relationship. We are not interested in rejecting the authority of science, but we do want to understand this authority in temporal terms, within a long history of scientific successes and failures, and in relation to other authorities on the experience and event of cancer.

Breast cancer activists' dependency on science came back to haunt them in the aftermath of the results of the LIBCSP studies. Activists played an important role in legitimating the capacity of scientists to provide answers about breast cancer and the environment on Long Island. They helped to create the illusion that science was capable of finding answers to complex questions about the relationship between breast cancer and the environment, in

12 Some reviewers found our use of the word 'science' to be problematically monolithic. There are of course many different sciences, and, as we show in this article, frequently scientists disagree with each other about what can and should be studied and how exactly to conduct studies. However, we sometimes use the term 'science' in the singular to demonstrate the way that 'breast cancer on Long Island' was most frequently framed, in media reports and in some scientists' and activists' accounts, as a story of science, and the incursion of activists into this domain.

13 We have conducted a thorough review of articles on breast cancer in both the *New York Times* and *Newsday* (Long Island's largest newspaper) between 1985 and 2005. Our goal was not to quantify the number of articles on 'breast cancer on Long Island', but to provide historical evidence of the object and its emergence and enactments. For media analysis on breast cancer coverage that does quantify this coverage, see Lantz and Booth (1998) and Brown *et al.* (2001).

the first place, simply by demanding and having won the LIBCSP. Media and other accounts reveal that the activists did not consider utilizing a counter-narrative available to them that would have rejected the position of science as a legitimate 'knower' of breast cancer and the environment altogether. Indeed, there were early, if less heard and taken up, articulations of this counter-narrative that suggested that the scientific community was ill-equipped to prove anything one way or another about environmental causation. For example, when asked to comment on the debate about environmental causes of breast cancer, a Harvard epidemiologist speculated in an article in the *New York Times* in 1992 that: 'It may be that it's beyond the capabilities of science at this time to measure these kinds of exposures and their effects' (Schemo, 1992). And, in response to the federal government's decision to mandate the LIBCSP, Dr Philip Nasca of the New York State Department of Health (NYSDH) emphasized the limitations of science and expressed his doubts about the National Cancer Institute's capacity to do such research:

Certainly there will be difficulties in developing a protocol and a scientific approach to studying these environmental problems. How are you going to measure the current exposures? And how do you determine past exposures? We know with some cancers there is a latency period of 10 to 30 years between the triggering exposure and the onset of cancer. (in Fagin, 1993)

What is surprising about Nasca's comments is not that he publicly questions science's ability to know a particular object, but that the complexities he describes become a reason not to attempt to do studies rather than the reason to try to find methods that will allow such studies to be done. The fact of the complexity of the object also becomes a means to delegitimize the knowledge and concerns of activists. Activists are deemed illegitimate knowers because they want to know something that scientists do not—yet—have the tools to know. Why then did scientists undertake a ten-year study if they suspected their findings would not be valid? Why did some in the scientific community come to pretend it could do something it clearly could not? It may simply have been because the studies were legislated, institutionally supported and because, quite crudely, there was suddenly a lot of money available to study breast cancer and the environment. But it may also reflect an underlying desire on the part of scientists to reclaim control over an area of knowledge that was increasingly being framed, articulated and even researched by activists and non-scientists.

Ironically, because activists relied on science to legitimate their claims about breast cancer and the environment, they created a space for it to do the opposite, to officially and very publicly delegitimize their claims, and with a voice activists had already touted as the authority on the subject. Many scientists, who all along had resisted the environmental hypothesis of breast cancer causation, have been quick to point to the LIBCSP study findings as proof that the environment does not play any role in the higher incidence of breast cancer on Long Island. For example, following the release of Stellman *et al.*'s (2000) study findings, Susan Sieber, a National Cancer Institute (NCI) spokesperson, promptly reasserted the hegemonic discourses of breast cancer causation—individual responsibility and demographics—to explain, once and for all, breast cancer on Long Island:

I think this new study does further substantiate what most of the other studies have found [It's] further confirmation that women need to look at factors in their life

over which they have control—such as diet, exercise, not smoking and using alcohol in moderation—that might protect against breast cancer, or at least might provide a healthy lifestyle that would enhance their chances of not getting cancer of any sort. (in Fagin, 2000: A-7)

Implicit in this comment is a policing of the domain between expert and non-expert. Women should be concerned about factors they can control, and these are factors related to personal lifestyle. Other factors are inevitably beyond their control, and therefore should not concern them. Also of note is the fact that, while environment does seem to play a part in cancer, in Sieber's assessment, it is only the environment that an individual personally creates. There is a refusal of a social responsibility for the environment. One might ask why asserting personal control over certain aspects of one's environment (in the form of, say, avoiding secondhand smoke or too much sun) is legitimate, while government control over environment (in the form of, say, greater regulation of pollution or pesticide use) is not legitimate. Encouraging personal responsibility for one's personal environment is an ideological move as much as encouraging social responsibility for environment understood more broadly.

In many respects, activists facilitated the compilation of scientific evidence that rejected their claims and demands. Marilie Gammon's findings in particular joined the mountain of evidence in favor of individual/demographic explanations of breast cancer—not because they proved anything 'more' about individual/demographic causes, but because they were intrinsically incapable of measuring or demonstrating anything 'significant' (by their own standards) about environmental causes (Gammon *et al.*, 2002a, 2002b, 2002c). Yet, before the LIBSCP was mandated, there were murmurs of doubt—from scientists no less—about the capacity of science to render a 'verdict' on the environmental hypothesis, given its limited methods. Activists—and many other players—placed a heavy onus on the LIBSCP in particular, and science in general, to legitimate 'lay' claims of a link between the environment and breast cancer risk. They waited on scientists to provide proof—rather than assert the need for environmental change on the basis of the legitimacy of their own knowledge claims. By the time the scientific results were published in 2002, few people still questioned the capacity of scientists to have rendered a verdict on the issue, and most people took this verdict, in these very specific studies, to mean that action on the environment was definitely *not* warranted. Many activist groups have responded to this by abandoning the issue altogether, although a few others have continued to emphasize environmental links to breast cancer on Long Island, and some have adopted the precautionary principle, which we will discuss at the end of this article. But, we are getting ahead of ourselves. Let's turn back to an earlier moment and earlier practices, before activists turned to science; let's turn back to the moment they became activists. The practice of turning back is an important aspect of our method for analyzing the complexity of an object. In order to understand an object in the present, we have to trace how that object came into being. To show how 'breast cancer on Long Island' emerged, we have to explore how women with breast cancer began to connect their experience of a particular illness with a particular place.

Mapping case 1: the West Islip Breast Cancer Coalition (WIBCC) pin map

In 1992, the West Islip Breast Cancer Coalition (WIBCC) was formed in order to study the incidence of breast cancer in the community of West Islip, New York. The origin story of the WIBCC is detailed in a recent book by journalist and activist Joan Swirsky (2005), and more briefly in various media reports on breast cancer mapping and/or incidence on Long Island. The story, now legendary for many breast cancer activists, goes something like this: in 1992, Lorraine Pace discovered she had breast cancer, and underwent a lumpectomy. When walking around her neighborhood just a few days after the surgery, she ran into 20 other women in a radius of eight blocks who also had breast cancer. Around the same time she attended a public meeting about breast cancer demanded by the newly formed Nassau County group 1 in 9 and sponsored by Senator Alfonse D'Amato, who was asking for federal intervention to review what Long Island women saw as the unsatisfactory results of an earlier Long Island Breast Cancer Study (LIBCS).¹⁴ The combination of these events—personal experience, the observation of a ‘problem’ in their communities, as well as the legitimation and politicization of this problem by activists and people in government, led Pace and eleven other women to form the WIBCC and begin a community mapping project.

The case of the West Islip pin map plays a critical role in the emergence of breast cancer activism on Long Island. It also represents an early counter-narrative to the more common assumption of the authority of science as ‘enumerator’ and ‘interpreter’ of breast cancer on Long Island. For a brief moment in time, the WIBCC—not the scientific community—was considered by many communities and activists (though, as we’ll see, not necessarily by scientists themselves) as the ‘expert’ on how to study the question of breast cancer and the environment on Long Island. A 1993 article in the *New York Times* describes Pace as canvassing for facts, and attempting to do ‘what few other researchers have ever done: Provide a statistical portrait, in map form, of the impact of breast cancer in a single community’, in the hopes that ‘the data will help unlock some of the secrets and maybe even help to determine whether there is an environmental link’ (Marks, 1993: B-1). In this article, Pace and her fellow activists are described as ‘researchers’, and their work is represented as of the same ilk as the work of scientific experts. But the article goes further: not only does it present Pace as a legitimate researcher, it also describes her as way ahead of the game in

14 See Note 3. The early LIBCS consisted of a series of six studies which found no links between breast cancer and the environment. However, neither did the LIBCS ‘disprove’ environmental links, except to rule them out in favor of lifestyle and demographic factors. Most activists wrote these studies off as an obvious effort by the State to privilege individual lifestyle and demographic risk factors over any environmental explanation. The LIBCS is often referred to as the ‘first’ Long Island Breast Cancer Study (followed by the Long Island Breast Cancer Study Project, or LIBSCP, which is the focus of our article). However, the two are not linked as scientific studies—indeed, the majority of publications on the LIBSCP do not even make reference to the LIBCS. While the LIBSCP was funded by Congress and the National Institutes of Health, the LIBCS was a New York State Department of Health initiative. The LIBCS relied heavily on interview and survey methods with women and review of historical records, whereas the recent LIBSCP involved blood sampling and lab analysis of body tissue, and environmental sampling and testing of things like soil and water.

The following reports were published as a result of the LIBCS: NYSDH, SUNY at Stony Brook Department of Preventive Medicine, & Nassau County Department of Health (1988, 1990a, 1990b); NYSDH (1990, 1992); NYSDH, Bureau of Environmental and Occupational Epidemiology (1992).

terms of developing unique methods to tackle the complicated question of the relationship between environmental factors and breast cancer. The WIBCC research is presented as a logical, legitimate and much-needed pursuit. The activists' mapping practices are portrayed as statistically valid and innovative methods that may help us to discover environmental causes of breast cancer; and they are also understood to address major gaps in knowledge that other 'experts' had so far refused to try to fill. Finally, as it is presented in the *New York Times* (Marks, 1993), the WIBCC mapping project is an early example of a proactive and precautionary approach to breast cancer and the environment, refusing 'scientific proof' as the only standard by which action should be taken.

The West Islip pin map gave birth to similar mapping projects all across Suffolk and Nassau counties. New groups proliferated, as did new community maps, while the number of women in what was now a breast cancer movement began to multiply. The WIBCC's spatial enactment of breast cancer in the form of community mapping practices inspired the spatial diversification and reconfiguration of breast cancer activism on Long Island itself. Mapping was not simply something done by women who were already activists; women became activists through the mapping of their communities. Moreover, surveying the community made the community anew: as a place that had a higher than normal incidence of breast cancer, perhaps for environmental reasons, and as a place that was politicizing itself through scientific practices.

What the WIBCC did was conduct a two-year, door-to-door survey, compiling information about household members' history of breast cancer, their length of residency, socio-demographic characteristics, and potential risk factors (Timander and McLafferty, 1998: 1627).¹⁵ They had a 61 percent response rate, and at the end of two years had surveyed 8,750 homes. In the course of their research, they created a 10-foot long map of West Islip on Pace's kitchen table, pinning yellow highlighted squares on it to represent the breast cancer cases identified through the survey, pink squares for benign tumors and blue squares where there were no tumors. The WIBCC mapping practices were distinct, epistemologically, from the spatial clustering and GIS (Geographic Information Systems) analyses that would eventually come to dominate breast cancer mapping on Long Island. Beyond the basic survey questions, and efforts to 'count' cases in West Islip as a whole, the mapping project was conceived to generate new knowledges through citizen dialogue. The activists sought individual and collective testimonies, encouraging memories of disease and environment. They collected an abundance of local environmental and historical information—much more nuanced and complex than that available in registries or state historical records. They did this by interviewing each other, older residents, breast cancer survivors and their families, and people who had lost loved ones to breast cancer over the years.¹⁶ Through

15 Sara McLafferty, one of the Hunter College geographers who analyzed the WIBCC survey and map findings (Timander and McLafferty: 1998), would later write about the methodological tensions between feminist geography and GIS in terms of how research is designed, informed, carried out and represented, as well as who is given access to it in the longer term. She uses the West Islip mapping project as a case study of her theoretical and methodological discussion (2002). We discuss both of these articles in more detail below.

16 There is no mention anywhere of these activities being tape-recorded or transcribed or 'formally' analyzed. We believe this was an informal process, carried out along with, and perhaps facilitating and enriching, the process of mapping and surveying. This 'qualitative data' was incorporated into the activists' everyday understandings and narratives of breast cancer on Long Island. These cultural memories of breast cancer and the environment on Long Island surface in many domains over the years, including in media interviews, political activities and demands for research, and in community consultations with scientists undertaking research on Long Island.

this process, the activists became witnesses to a history of disease in their community, and as a result of their practices of witnessing, they came up with many theories about breast cancer and the environment. Indeed, by the end of their work, they had identified what they thought were several breast cancer clusters. They believed that they had found signs of clustering in women living near the shore, at the end of water mains, on dead-end streets, and near a hazardous industrial site in West Islip.¹⁷ Only after they had collected their own data and come up with their own theories did they seek help from outside experts.

Mapping case 2: WIBCC data and space-time cluster analysis

The outside experts the WIBCC turned to were Linda Timander and Sara McLafferty, geographers at Hunter College in New York City. In 1998, Timander and McLafferty published a spatial clustering analysis of the WIBCC data, which asserted that there was little evidence of clustering among cases of breast cancer in West Islip, New York. Without challenging the study's careful statistical analysis of the data, we want to analyze briefly how this study (and McLafferty's later use of the WIBCC mapping project as a case study for a comparative analysis of feminist geography and GIS) frames the mapping practices of the activists in particular, and scientific studies into links between breast cancer and the environment more generally.¹⁸

In her later discussion of the WIBCC as a 'grass-roots effort' that would be 'transformed into a multimillion dollar GIS' (through the LIBCSP-GIS), McLafferty notes that the Long Island activists turned to GIS in a 'desire to *know* about significant health and environmental issues in their community and regional context' (2002: 264, original emphasis). McLafferty then describes how the 'activists embraced mapping and GIS as intuitive means for exploring spatial and environmental associations' (2002: 64). Why does McLafferty assume this decision was 'intuitive'? Was it *intuition* that led the activists to mapping and later to trained geographers or *knowledge* about what methods they needed to collect and analyze their data? In McLafferty's article, and even more so in Timander and McLafferty's earlier publication of their spatial clustering analysis of the WIBCC data, the mapping practices of the activists are not framed as scientific practices. Despite the use of the WIBCC data to publish a paper in a respected academic journal (*Social Science and Medicine*), the geographers are quick to point out the problem of 'the simplistic nature of the questions', which meant the study could not 'account for the different categories of benign breast disease and their associated risks' (Timander and McLafferty, 1998: 1627). The authors go on to explain that the 'research is somewhat limited by the accuracy and completeness of

17 Undoubtedly they had many other theories, but these are the ones mentioned by McLafferty (2002: 264). Long Island activists presented a wealth of historical clues and environmental issues they wanted investigated through the later LIBCSP-GIS. They came to the GIS community consultation meeting equipped with knowledge that only their own, local research and discussions could have generated. These collective, community suspicions and memories of environmental events and sources of pollution were not accounted for in the GIS, because 'valid' historical records could not consistently back up the activists' claims.

18 Timander and McLafferty explain that the spatial clustering methods they use take into account both known risk factors, including age, race, socio-economic status, age at first menarche, age at menopause, and age at first full-term pregnancy, and 'migration bias by focusing on women who have lived at their current residence for 30 years or longer' (1998: 1623–1624).

the survey information', a problem with all scientific research, but here used to emphasize again that the data was gathered by non-experts:

Since the survey was conducted by local residents, the sampling strategy and wording of questions were occasionally problematic. Although the WIBCC made heroic efforts to reach all local women, gaps remain, and we do not know how those might affect the outcome of the research. The accuracy of responses also may be questionable, especially for the more detailed medical questions on topics like benign breast disease. It would be interesting to conduct a similar investigation, utilizing more extensive health data bases such as New York State's cancer registry data, to check the validity of these findings. (Timander and McLafferty, 1998: 1634)

There are many assumptions in this quotation, some about the WIBCC and some about scientific knowledge practices. The first thing one should note is that WIBCC members are described as 'local residents' and not 'researchers' or 'experts'. They did have a 'sampling strategy', which gives their work some credibility, but the wording of their questions was 'occasionally problematic', implying that experts are always better at wording their questions. The WIBCC are 'heroic' in their attempts to survey all the residents of West Islip, but still 'gaps remain', which again suggests that when experts do studies no gaps remain. In fact, the more than 60 percent response rate to the survey isn't just 'heroic', it is, quite simply, a statistically sound response rate to a survey. Finally, the suggestion that the New York State cancer registry data would supply better data forgets an entire history of the failure by the State to collect and update the data in the registry, which was one of the factors that precipitated the WIBCC to act in the first place.

There are two other aspects of Timander and McLafferty's article that we want to address briefly: one regarding their method and one regarding their conclusion. Timander and McLafferty state that the methods they use to analyze the WIBCC data are better than some other methods of space-time cluster analysis because theirs accounts for 'known risk factors for disease and thus may identify spurious spatial clusters' (1998: 1623; see also note 13). One of the known risk factors for disease that Timander and McLafferty account for is 'family history of breast cancer', which means that family history in their study has been classified as having nothing to do with environmental factors. Although we are not suggesting that a family history of disease can never be explained by genetic factors, or that it is unusual, scientifically, for this history to have been excluded in the statistical analysis of the WIBCC data, we do wonder how family history, and indeed even genetics, can be separated so cavalierly from environmental factors. This is an ontological more than an epistemological question: what is the category 'family history of breast cancer'? How does a 'family history of breast cancer' come into being in the first place? What happens to our ability to produce knowledge, scientific or otherwise, when 'family history of breast cancer' is delimited as a category wholly separate from environmental factors?

In their conclusion, Timander and McLafferty assert again in no uncertain terms that their analysis found no clusters that could not be explained by known risk factors. And yet, in the end, they also acknowledge the limitations of their own study. They tell their reader that, 'the causes of 62% of breast cancer cases among long term West Islip residents remain unknown' (1998: 1632). They also reiterate that their negative findings do not indicate that breast cancer is not a problem in West Islip, and argue that their findings should

not be used to normalize breast cancer incidence in West Islip. Instead, they suggest that what might be needed is a wider view of the problem:

It is quite possible that West Islip is a cluster in and of itself, or part of a larger cluster. In its design, this study is confined to the community of West Islip; clusters across or outside the community boundary cannot be identified. Cases located near the boundary may be part of a larger cluster that includes cases in a neighboring town, or the entire community may be a cluster within a much larger Long Island cluster. Research at smaller geographical scales, focusing on Long Island as a whole, is needed to unravel these patterns. (1998: 1632)

As Timander and McLafferty argue, our methods must be able to analyze multiple scales at once in order to reveal the complexity of an object. How does breast cancer in West Islip relate to breast cancer on Long Island or, for that matter, to breast cancer on the north-eastern seaboard of the United States? We must find ways to connect micro- with macro-analyses. We must learn to map the relationship between very small things—like genes and individual bodies—and very large things—like family histories and the environment of an island in the northeastern United States.¹⁹

Mapping case 3: New York State Cancer Surveillance Improvement Initiative (CSII)

The final case of mapping that we want to look at is the New York State Cancer Surveillance Improvement Initiative, which published a report on its findings in 2000 entitled ‘Breast cancer in New York State by zip code, 1993–1997’.²⁰ This initiative has been criticized by some activists for excluding them from the design of the research.²¹ The CSII report

19 In *Man-made breast cancers*, Zillah Eisenstein makes a similar argument through her articulation of the uses of theory. In her analysis, she describes theory as a ‘way of seeing connectedness—of the breast to the rest of the body; of the body to the rest of its environments; of the historical process over time, which triggers cancer mutations, to the fluidity of borders between the breast and all else. Theory allows me to see beyond singularity and inevitability’ (2001: ix).

20 This report is available on the New York State Department of Health website: www.health.state.ny.us/nysdoh/ (accessed July 2005); see also <http://www.health.state.ny.us/diseases/cancer/csii/> (accessed April 2007).

21 Notably, the LIBCSP-GIS has also been criticized for excluding activists from the design of the research, as well as for denying them access to the research results. The National Cancer Institute has restricted access to the LIBCSP-GIS to ‘experts’, who must apply to view the data. ‘Non-experts’ can only view the larger maps produced by the project and not the maps that refer to smaller geographic areas or specific addresses. In an article in *Newsday* in 2002, Ellen Heineman, the NCI epidemiologist overseeing the LIBCSP-GIS, was interviewed, and her comments illustrate the policy of exclusion, as well as the traditional territorialism of science in maintaining exclusive access to its own tools in order to produce knowledge according to its own rules: ‘We’re going to give the public a glimpse of the inner workings of a GIS, but they won’t get to access the tools or a lot of the data’ (in Fagin, 2002c). Journalist Dan Fagin adds, ‘She said that non-scientists who won’t understand the limitations of the GIS might draw conclusions about links between cancer and pollution that aren’t supported by science’, and quotes Heineman again, ‘We don’t have the capacity to provide the training and give them the expertise they would need to use these tools’ (2002c). Ironically, the legitimate ‘experts’ seem not to want anything to do with these tools. Fagin’s article also reports that between 2000 and 2005, not one ‘expert’ applied to the NCI for access to the LIBCSP-GIS data, despite the supposed detail of its data. Reasons for this may include the general delegitimation of the hypothesis that breast cancer on Long Island has environmental causes. It’s possible that scientists do not think they will find any meaningful environmental connections, particularly in the wake of Gammon’s study findings.

is a curious document, from its title, which suggests the main concern of the State of New York is to improve its cancer surveillance rather than to reduce its cancer incidence, to its framing of the issue of cancer in New York State, to its presentation of the color-coded maps. Everything about the document suggests an attempt by the State to allay public fear, which of course is often an important goal of public health work. But, more to the point, it also reads as an attempt by the State to pacify its citizens, and to deflect responsibility for high rates of cancer from the State onto individuals and their personal habits. Despite the State's attempt to control the terms of the discussion through the release of this report, the publication of the CSII report has had some unintended effects, which we will discuss below.

Essentially, the State's CSII maps recycle incidence data that was already available to the public in table form. In other words, the State simply transferred data from tables to maps rather than embark on a new mapping project. These maps provide no new information in terms of overall incidence or distribution of breast cancer across space, and no information at all about the relationship between breast cancer and environmental factors, which was what activists had long sought. The various maps show New York State counties divided into zip code areas. The use of zip codes to show the distribution of cases is explained as a means of protecting the privacy of individuals with cancer. Thus, one of the frequently asked questions (FAQs), which are used to present the report's information in a user-friendly manner, asks: 'Do the maps show where people with cancer live?' And, in response, the report tells us, 'By law, New York State must keep information about individuals with cancer confidential. To protect their privacy, we cannot show on a map where each person with cancer lives.' And yet, what the State fails to mention is that to protect the health of the public, we probably need to do just that. On the maps, the zip code areas are color-coded to indicate the degree to which the incidence in a particular zip code reflects or differs from the 'expected' rate, which is calculated on the basis of the statewide average. If this seems like a circular argument, it's because it is. Nowhere does the report suggest that this 'average' might itself be considered unacceptable in contrast to incidence rates in other states or to rates for New York State in the past. The statewide average for breast cancer is now 131.5 cases per 100,000 women compared to an average of 82.9 cases per 100,000 women between 1978 and 1982 (NYSDH Bureau of Cancer Epidemiology, 2005a), but this fact is not mentioned in the report, which provides no comparative data between past and present incidence or between the State of New York and other states, regions or nations.

In answer to the report's opening question 'What is the New York State Cancer Surveillance Improvement Initiative?' we are presented with a story of government responding to its citizenry. Notice, however, that there are no activists in this story, nor even any citizens who know much about breast cancer or the process of mapping disease: 'In April 1998, New Yorkers asked Governor Pataki for help. They wanted to learn more about cancer in their communities. The Governor asked the State Health Department to find easy to understand ways to do this.' Indeed, knowledge about cancer is all on the side of the State, and the problem is not cancer in New York State, but the difficulties for the State in communicating knowledge about cancer in ways simple enough for its citizens to understand. Again, the State's overarching concern seems to be to control the response to this knowledge by its citizens, who are portrayed in a patronizing way as not able to handle most forms of scientific knowledge.

According to the CSII report, the goal of the project 'is to provide New Yorkers with information about cancer' and to 'guide future research on the causes of cancer and cancer prevention programs'. It explains that 'scientists taking part in the project are looking for the best ways to map where cancer patients live', and notes the risk factors the scientists are investigating: 'things in people's lifestyles, medical history or the environment that may increase a person's chances of getting cancer'. In a sidebar that defines certain key words in bold type in the main text, 'risk factor' is defined further as 'something that has been associated with an increased chance of getting a disease'. This definition again lists risk factors for cancer, including 'personal risks (family history of cancer, diet, and many others) as well as exposure to cancer causing agents (smoking, sunlight, x-rays, certain chemicals, etc.)'. We quote at length from the text to show the way 'personal risk' and 'lifestyle' are emphasized over environmental factors, which, in the definition of 'risk factor', are still in a sense contained under the rubric 'personal risk', because 'smoking' and 'sunlight' can be understood as having as much to do with environment as personal lifestyle. We also want to emphasize once again the problem of the construction of categories. In the CSII document, 'personal risk' and 'lifestyle' are categories that are understood as separate from the category 'environment'.

This emphasis on personal factors is even more pronounced in the section entitled 'About Cancer'. In answer to the question 'What causes cancer?' we are told that, 'Our personal habits and lifestyle may contribute to most cancers. It is believed that about 30% of cancer deaths are due to tobacco and 35% may be related to diet.' There are no references for these statistics; apparently including references is not an 'easy to understand' means of presenting information. Still, the passive construction of the sentence signals the tenuousness of these scientific 'facts'. In another side bar, the CSII report offers several 'Tips for Lowering Cancer Risk', reiterating the report's overall neoliberal discourse of personal responsibility. Although the side bar acknowledges that, 'many risk factors for cancer are unknown', it nonetheless also asserts that, 'there are some things you can do to help lower your risk of developing cancer'. The tips include not smoking, getting regular check-ups, eating high-fiber, low-fat foods, exercising, and drinking in moderation. They also suggest that one should '[a]void exposure to known carcinogens . . . unnecessary x-ray, [and] . . . too much sunlight'. Finally, one should '[d]iscuss the risk of hormone replacement therapy with your doctor' and '[b]e aware of health and safety rules at work and follow them'. These are all privatized responses. There is no sense in the report that one might work with others to, for example, prevent the proliferation of carcinogens in the environment, lower the emission of greenhouse gases that cause the depletion of the ozone layer, or critique the medicalization of menopause. And there is no sense in the report that one might politicize cancer in particular or health care in general.

The report then moves from a discussion of cancer generally to the specific case of breast cancer. To explain the particular focus on breast cancer, an FAQ asks: 'Why did you map breast cancer?' Once more, the report is silent about activism in New York concerning higher-than-normal breast cancer incidence, noting only, 'Breast cancer was mapped because it is one of the most common cancers among women in New York State.' The implication of such a statement is that the State maps diseases that are common, not those whose rates are uncommon and need to be explained. The report further normalizes these numbers by also normalizing the steady increase in women diagnosed with breast cancer. The report

explains this increase with several scientific facts: women are living longer, the baby boom generation is aging, and more breast cancers are detected earlier because of better screening technologies. The State does not mention that these factors do not sufficiently explain the steady increase in breast cancer incidence in general, never mind in the particular case of breast cancer in New York State.

In the final section of the report before the presentation of the maps themselves, we are told ‘how to read the maps and index’. This section can be synthesized into a single sentence: these maps tell us nothing about cancer causation because cancer causation cannot be mapped. Because ‘[c]ancer develops slowly in people’ and because people move frequently, the report states that we cannot explain the relationship between cancer incidence and particular environments. Sounding eminently reasonable, the report states that the ‘environmental risk factor data available to us for mapping is quite recent, but it usually takes a long time for cancer to develop after someone is exposed’. Environmental risk and cancer appear to exist in two different temporalities that cannot be brought together in the space of a single map. To suggest that we create methods to attempt to do just that is implicitly presented in this report as scientifically naïve. The final FAQ in the report is tellingly not ‘What can the State do?’ but ‘What can I do?’ Because in this neoliberal model of breast cancer causation, preventing breast cancer is first and foremost each citizen’s personal responsibility:

If you are concerned about your risk for getting cancer, there are things you can do. First, talk with your health care provider about your personal risk factors. Talk with your relatives about your family. Is there a family history of a specific type of cancer? If so, you should give this information to your health care provider. You may also want to find out about cancer screening programs that are available in your community and discuss them with your health care provider (CSII report, 2000).

The report recommends that citizens of New York gather information, but only about family history and screening programs. This information should then be given to health care providers, who are portrayed as the final arbiters of the usefulness of the information that citizens gather. What citizens are encouraged to do, finally, is become good consumers of medical care. What they are not encouraged to do is become experts themselves on the complicated relationship between cancer and the environment.

The CSII maps have been criticized as a waste of resources, and an empty gesture by Governor Pataki in his effort to appear to be doing something about cancer in New York, all the while avoiding costlier measures that might involve action on the environment, or even research that might lead to such action. Despite the intention of the State to dispel fear, the CSII maps provided little comfort to the citizens of New York. Rather than quell citizens’ concerns about cancer and the environment, the publication of the maps increased those concerns. Indeed, the State seems to have been right to worry that the maps would be misread, or read in a way contrary to the way the State wanted them read. Despite the State’s assurances that the CSII maps definitively do not show a link between the environment and cancer, many citizens read the maps as indicating just that.

The maps gave the public a striking visual rendering of the high rates of breast cancer in their communities. Breast cancer incidence in some areas was a whopping 24 percent above average. Public angst shot up and public hearings were held. A *Newsday* article quotes one

citizen as exclaiming, ‘it’s just like in that movie, *Erin Brockovich*’ after one such hearing about the maps (Fagin, 2002e). For the first time, the State acknowledged breast cancer clustering on Long Island, particularly in the zip codes for Port Jefferson, Mount Sinai and Coram, and agreed to undertake research to search for causes in these three communities. The Coram, Mount Sinai and Port Jefferson (CMP) Follow-up Investigation focused on very specific neighborhoods. This also meant that the CSII would not, in the end, lead to large-scale mapping of environmental factors for Long Island and New York State as a whole, or research into breast cancer and the environment in other zip codes.

The results of the CMP study were recently released: the study concluded that overall levels of contaminants were not higher in these zip codes than for the rest of New York State; that breast cancer prevalence could not be linked to those contaminants that were tested at elevated levels; and that the rates of breast cancer in these zip codes were not significantly higher than the rest of New York State, when demographic and lifestyle factors were taken into account (NYSDH, 2006). Again, we witness explicit acceptance and efforts to represent as ‘normal’ what are already extremely elevated levels of breast cancer rates and contaminant levels in the rest of the State. Rather than provide an impetus for environmental and health interventions aimed at decreasing levels of breast cancer and environmental contaminants, the CSII and CMP studies have simply reinforced the State’s argument that nothing needs to be done, since Long Island is unremarkable in relation to the rest of the State. Further research by the NYSDH into the links between breast cancer and the environment on Long Island—or in New York State as a whole—now seems highly unlikely.

Turning Away from Science: Burnout

Activists’ reactions and practices in the ‘post-2002’ period reveal just how much they had come to rely on science’s ability to legitimate the assertions of the breast cancer movement on Long Island. The failure of science to do this has forced activists to rethink their strategies, and this has led to the emergence of new practices. While many, if not most, activists have turned away from research practices to educational and support practices, a few groups have asserted (or reasserted) the legitimacy of the activists’ own expertise on the issue of breast cancer and the environment, their own forms of research, and their own bodies as ‘proof enough’ that precautionary action on the environment should be taken.

In July and August 2002, a series of articles by Dan Fagin entitled ‘Tattered Hopes’ appeared in *Newsday*. This series addressed the failure of both the LIBCSP and the CSII mapping project to prove an environmental link to breast cancer, and explored what this failure meant for breast cancer activists. Tipped off by a scientist on Gammon’s team that the results were ‘not going to be earth shattering’, several activists were interviewed about the negative findings of the LIBCSP just prior to its release on 6 August. Their statements reveal once again just how much they had considered the LIBCSP to be the culminating event of the movement as a whole, and the profound sense of devastation they felt at its failure. The statements also reveal a particular understanding of the temporality of activism. There is a sense, among activists especially, but also among some scientists, that they had hoped for—expected even—a single moment of revelation, when the question of the relationship between cancer and the environment would be explained once and for all. But, it

seems to us, that the complexity of ‘breast cancer on Long Island’ challenges this temporality of activism as much as that of science.²² The current president of the West Islip Breast Cancer Coalition, Virginia Regnante, expressed her dismay by stating uncategorically that, ‘The fight against breast cancer that we started in the early 1990s is dead in the water. What have we done in the past 10 years? Really, nothing.’ Geri Barish, 1 in 9’s long-time president also sounded demoralized:

You put in all the time and effort to get the study, and go through all the excitement of ‘My God, now we’re really going to get an understanding of why we get cancer.’ And then 10 years passes and you realize, ‘My God, we’re still in the same place.’ So there’s a lot of frustration, a lot of anger. It’s very easy to get depressed and say, ‘I’m tired. How much more can you do?’ (in Fagin, 2002a)

Similar feelings of burnout have led many women to end their involvement in breast cancer activism altogether.

While some women have remained active in the movement, many others have abandoned the effort to push for scientific research on the possible link between environmental toxins and breast cancer. According to the *Newsday* series, Barish has turned her attention to the support and education services provided by Hewlett House; Lorraine Pace, former president of the WIBCC, has also focused on education in her position as a breast cancer educator at Stony Brook University; and the WIBCC itself now concentrates mostly on its support services (Fagin, 2002b). A review of Long Island area breast cancer organization websites²³ shows that the primary emphasis is currently on support and education over political demands for scientific research into environmental causation. While 1 in 9 does continue to advocate for further research into the causes of breast cancer, their push is now for research into genetic rather than environmental factors, which suggests once again that the genetic and the environmental are being formulated as mutually exclusive categories. Nonetheless, while Barish’s ‘My God, we’re still in the same place’ can certainly be read as a sign of burnout, we also want to read it as a sign of a problem that requires a new approach, one that acknowledges that perhaps all along we needed to be actively changing the place—that is, the environment of Long Island—as part of our practices of mapping breast cancer on Long Island. We want to think about mapping as a temporal as well as a spatial practice that, by taking account of the long term, anticipates a different future.

Turning away from scientific proof and toward mapping the future: the Huntington Breast Cancer Action Coalition (HBCAC) and the practices of precaution

The failure of scientific studies to prove environmental causes of breast cancer has led some activists to take new paths, and they have embarked on these new paths by revisiting some

22 Thanks to Victoria Hesford for helping to clarify this point.

23 See for example, the websites for breast cancer organizations in South Fork (<http://www.southforkbreast.com/>), Babylon (www.babylonbreastcancer.org) and Brentwood/Bayshore (<http://home.att.net/~bbbcc/>).

earlier practices of ‘breast cancer on Long Island’.²⁴ In an article that appeared in *Newsday* a week and a half after Gammon’s disappointing study results were made public, Barron Lerner, author of *The breast cancer wars* (2001), urged activists not to give up their struggle (Lerner, 2002). The article was entitled ‘What if proof is elusive?’ and in it Lerner suggests it is time for people—including scientists themselves—to admit the very likely possibility that ‘there may be a connection [between breast cancer and the environment], but due to limitations of scientific technique, it cannot be proved’ (2002). He notes how ‘some Long Island activists are insisting on more, and better, scientific studies of the environmental connection to breast cancer’, and praises their ‘admirable track record of promoting good science’ (2002). Nonetheless, the point of his article is to counter the assumption among many activists that scientific proof must *precede*, and authorize, action on the environment. Instead, he advocates the ‘precautionary principle’, and asserts that:

... at some point activists and researchers should acknowledge that a link between breast cancer and environmental toxins, if it exists, may be impossible to prove. Does this mean the quest to rid Long Island and other areas of toxic waste and pollutants should be abandoned? Absolutely not Rather, we can push aggressively for laws that eliminate or regulate other potential carcinogens, notwithstanding the lack of conclusive studies. (2002)

In another article commenting on the LIBCSP results, Barbara Brenner, director of Breast Cancer Action in San Francisco, notes how ‘most reporters interpreted the results as proof that pollutants did not cause breast cancer’ (2003: 48). She outlines the study’s limitations, and urges activists to start engaging in ‘the essential political work needed to reduce everyone’s exposure to these kinds of substances’ (2003: 48). Like Lerner, she advises activists to implement a precautionary principle of public health, since scientific research methods as they are currently conceived are unequipped to generate ‘proof’ of harm. She insists, ‘we cannot let the process of science hold us back from working toward policies that will reduce the chemical exposures we all experience’ (2003: 48). Breast Cancer Action has been guided by this approach since its emergence in the early 1990s—as have been many other organizations across the US and UK,²⁵ though not, as we have seen, groups on Long Island, at least not until after the publication of the failed studies in 2002, a moment that marks an important shift in and diversification of activist practices.

A key concern of this article is to understand the significance of Long Island activism as framed as a story of science. However, the Long Island movement may be contextualized further in relation to what are now diverse cultures of activism existing within ‘health movements’ in general, and a larger ‘breast cancer movement’ in particular. According to Brown *et al.* (2004), there are three major categories of Health Social Movements (HSMs). These

24 This is precisely the moment when an ethics of failure can offer a useful counter to a demand for certainty. Articulating an ethics of failure leads not to paralysis in the face of failure, but to the search for new methods and practices of science and politics (Diedrich, 2007: 148–150).

25 For further discussion of the precautionary principle and organizations that have designed their activism around it, see Davis *et al.* (1998) and Potts (2004). For Davis *et al.*, the precautionary principle is a theory that offers a new temporality of disease. They call for longer-term studies, noting that, ‘[t]he process of cancer alters metabolism in ways that are not well understood. Given the complex and competing roles of xenohormones, only long-term prospective studies that cover two generations will be able to resolve the issue of the relative roles of prenatal, prepubescent, and subsequent exposures to harmful and beneficial xenohormones’ (1998: 527).

are: health access movements (which seek equitable access to health care and improved services); constituency-based movements (which address health inequalities and inequities based on race, class, gender and sexuality); and embodied health movements (which emphasize personal and embodied experiences of illness in social movements; challenge science on etiology, diagnosis, treatment and prevention; and demand participation in scientific decision-making and processes to remedy oversights and biases). Breast cancer activism on Long Island might be categorized as primarily an ‘embodied health movement’, but in a much more specialized way than as defined by Brown *et al.* Long Island activists demanded that they be allowed to participate in scientific research, and they collaborated with scientists in various capacities over the years. Their challenge to science was primarily in terms of its neglect of prevention-oriented research—rather than in terms of treatment or diagnostic research. Even more specifically, they challenged science for what they perceived as a neglect of environmental, prevention-oriented research on Long Island—as a particular place with a particular history of a problem. As such, breast cancer activism on Long Island might in fact be best described as a ‘constituency-based’ embodied health movement, one whose constituency is based primarily on a politics of geographical identity rather than on a shared experience of social disadvantage.

Breast cancer activism on Long Island also differed in several respects from that of the National Breast Cancer Coalition (NBCC), and even from what is commonly understood as ‘the US breast cancer movement’ as a whole. Long Island activist groups were members of the NBCC and were certainly involved in national protests, signature campaigns and broader efforts at the federal level to meet the array of health-related goals espoused by the NBCC. Like the NBCC, the main demands of the Long Island groups were for more research funding and media attention. Unlike the NBCC, issues related to improving access and quality of breast cancer diagnosis and treatment services—as well as the focus on minority and disadvantaged groups’ experiences with the disease and the health system—did not figure as prominently on Long Island.

Maren Klawiter (2004) describes breast cancer activism in ‘two regimes’ over time in the San Francisco Bay area. During the 1970s and 1980s, the hegemonic regime of activism was of the fleeting mobilizations of groups of people with varying ideologies, sometimes within pre-existing social movements and organizations (including, for example, the larger feminist movement, the women’s health movement, the patients’ rights movement), in order to critique biomedical treatments for breast cancer (drive-through mastectomies, radical mastectomies, informed consent issues) and/or to set up support networks for people with breast cancer. In the 1990s, the ‘breast cancer movement’ proper emerged, and was centered around the NBCC. Klawiter argues that the NBCC did not play a central role in San Francisco, however. Rather, she found there were three different ‘cultures of action’, constituting a ‘field of contestation’ in and between a diverse array of organizations, which together make up her second regime of breast cancer.

The ‘mainstream’ movement, Klawiter and others²⁶ argue, is corporatized, institutionalized, and highly popular in the press and political arenas. It ‘replaced the stigmatization, isolation and invisibility of women with breast cancer with a new public culture overflowing with symbolic gestures of support, solidarity, respect and recognition’, and was built around

26 For other critiques of the ‘mainstream’ breast cancer movement, see Ehrenreich (2001) and King (2004).

an array of corporate names and celebrities who adopted breast cancer as their *'cause célèbre'* (Klawiter, 2004: 847). It included the development of organizations aimed at raising money for medical research and to provide mammography for low-income women. This description certainly resonates with Long Island breast cancer activism, which also generated a public culture of support from politicians, the media and corporate sponsors. Breast cancer is frequently described by public figures as Long Island's *'cause célèbre'*, and, through the years, the activists have used celebrities like Carol Baldwin (mother of the Baldwin brothers) and Phyllis Newman to promote their cause. However, even as a relatively mainstream movement, Long Island activism still posed a forceful challenge to government (at both the federal and state levels), science and, much more indirectly, polluting industries.

Klawiter also describes feminist cancer activism, which challenges optimistic narratives, rejects the production of a normalized femininity signaled in the plethora of pretty pink ribbons and the hegemonic practices of prosthesis and breast reconstruction, engages in direct political action and social justice work, and includes many lesbian organizations. Feminist cancer organizations usually promote an environmental analysis of cancer, and, during the second half of the 1990s, started to work very closely with the environmental movement on various issues. They have also usually articulated a clear anti-capitalist and anti-corporate critique of what some have called the cancer-industrial complex.²⁷ Klawiter argues that, over time, many feminists went from viewing breast cancer 'solely through the lens of gender and sexuality' to understanding it as 'an environmental disease and an issue of profits and pollution' (2004: 863).

Breast cancer activism on Long Island in general might be understood as reflecting aspects of both the mainstream breast cancer movement as well as feminist cancer activism, though we should be clear that some of the Long Island activists distanced themselves and their movement from feminism.²⁸ Long Island activism has been mainstream in its harnessing of a 'public culture of support', and has not articulated a critique of capitalism and profits over people/health. However, it has clearly challenged the State and scientific community for neglecting an important women's health issue, and demanded that attention be paid to environmental factors and that there should be a shift to a focus on prevention. At the same time, it has had less of a social justice component than the feminist activists described by Klawiter. Issues of class and race have not figured prominently in Long Island activist groups' articulations of women's needs and interests with regard to breast cancer.

Another difference between feminist breast cancer activism as delineated by Klawiter (2004) and Long Island breast cancer activism is that most Long Island breast cancer groups have not adopted the precautionary principle to guide their activism on breast cancer and the environment, even after the studies were released in 2002. However, the Huntington Breast Cancer Action Coalition (HBCAC) has recently done so, and it has also retained a focus on the environment even in the wake of the LIBCSP findings. According to *Newsday*, the Huntington group is now the most politically active group on Long Island (Fagin, 2002b). It continues to organize marches and demonstrations, to push for research on environmental causes of breast cancer, to fight the State for access to its well-guarded

27 See, for example, Ehrenreich (2001) and Eisenstein (2001). Audre Lorde referred to the cancer-industrial complex as 'Cancer, Inc.' in *The cancer journals* (1980).

28 We should also note that some of them, especially Barish, became active in New York State Republican Party politics.

CSII database, and to demand that the State fulfill its original promise to do something with the CSII maps that seem to indicate breast cancer clusters in Long Island communities. The HBCAC has also begun to reconceptualize its relationship to science, and in spring 2005, their newsletter was devoted to explaining the precautionary principle and how ‘Huntington [is] a pioneer in this field’ (Bottiglieri, 2005). In a recent report on their community mapping activities, they describe their rationale and vision in the following way:

Today, a wide chasm has opened up in the environmental health field. On the one side are government officials and academics, who feel that mapping exercises should continue to focus on research. On the other side are the environmental health advocates and some environmental health scientists. They believe cancers are a direct result of industrial era chemicals [T]hese concerns have also led HBCAC to promote a new public policy initiative, the ‘Precautionary Principle’: when an activity raises threats of harm to human health or the environment, precautionary principles should be taken even if some cause and effect relationships are not fully established scientifically.²⁹

Under this new policy, the HBCAC has taken on many campaigns and practices that are not related to demands for scientific research. For example, in 2004 it petitioned the Environmental Protection Agency (EPA) against its decision to deregulate a portion of radioactive waste on the Island, citing the need for precaution. It played a central role in the New York State Breast Cancer Network’s (NYSBCN) action to put forward the Public Health Protection Act in the New York State Legislature on 12 April 2005, which is a legislative enactment of the precautionary principle. Similarly, the HBCAC has worked with Assemblyman Tom DiNapoli and State Senator Carl Marcello to develop bills that mandate the precautionary principle ‘as a model for doing business and living in New York State’, and promote green labeling for all New York State products, ingestible or not. It has also worked on a procurement bill that requires that all New York State agencies consider the safest and healthiest options when buying goods or developing protocols for schools, state offices and highways. These activities are qualitatively different than the research-focused demands of the past because they call for action on the environment in the absence of scientific proof of harm.

But is the HBCAC rejecting scientific authority and expertise through its recent adoption of the precautionary principle? Laura Potts argues that the precautionary principle is a more proactive alternative to the scientific proof principle, but still remains rooted in the traditional epidemiological or public health paradigm. It does not propose ‘unscientific’ methods for determining public health risk, or for justifying proactive environmental action. Rather, it changes the measure by which science might be seen as having provided adequate data to warrant action. Within this framework, ‘sufficient evidence’ rather than ‘proof’ is required to act on the environment (Potts, 2004). Alternatively, some advocates of the precautionary principle shift the burden of proof to polluting industries, arguing that they should be the ones to show, scientifically, that their products pose no harm. In this way the precautionary principle is still premised on the authority of science to provide evidence or proof of harm, or not, as the case may be. Despite this attempt to shift the burden of proof, this approach can also leave open the possibility for non-action in the political arena. People who are

29 ‘HBCAC’s Mapping Project chosen to present at the ESRI International Conference’, at www.hbcac.org/mapping.html (accessed July 2005).

resistant to action on the environment have argued that the weight of scientific evidence remains insufficient, and that therefore more research is needed before any action need be taken. This politics of inaction in the present gets rationalized through the perpetual promise of future studies.

In the wake of the release of her failed studies, Marilie Gammon's statements to activists reflect this position. She would not venture to give them advice about how to avoid harmful environmental exposures, since there was no proof of a problem. She told them 'what this study says is that we need to do more research before we can get to the point of giving advice' (in Fagin, 2002d). Similarly, industry supporters can argue that 'proof of no harm' exists when science fails to prove an environment-breast cancer connection. We argue that these two positions represent two different attitudes toward the future, and these attitudes affect how we approach both scientific research and political activism. The precautionary principle attempts to anticipate problems, takes account of future generations and seeks to generate a guarantee for the future through particular actions in the present.³⁰ The scientific proof principle claims that we can't know anything about the future, and so is always belated in its engagement with the present. We can only really know something when it's already too late to change the situation that brought the object into being in the first place.

The HBCAC supports a precautionary, public health paradigm in its approach to the potential relationship between cancer and the environment, and it also explicitly advocates for more scientific research on the environment. At the same time, however, it asserts the legitimacy of non-expert knowledge practices about breast cancer and the environment, particularly those generated through its own mapping project, and it bases its precautionary political demands as much on its own research findings as scientifically generated evidence. Activist mapping practices are used to authorize precautionary practices. The HBCAC presented its mapping project at the Environmental Systems Research Institute Inc. (ESRI) conference, where 'a major theme of the talk was to explain to public health professionals (in the public and private sector) the importance of community-based mapping projects for public health initiatives'.³¹ The HBCAC underscored the legitimacy of activist-generated knowledge about breast cancer and the environment:

The government and research scientists are not paying adequate attention to the environmental factors that are contributing to breast cancers on Long Island and elsewhere Community-mapping projects are distinctive because local citizens, often working through non-profit organizations, control the mapping process. They control what is to be mapped, how maps are to be distributed, and how they are to be publicized.³²

30 This resonates with Kim Fortun's discussion in *Advocacy after Bhopal* on what she describes as her:

... commitment ... to understanding how advocates responding to the Bhopal disaster have anteriorized the future—through legal precedents and the structure of rehabilitation schemes, but also more subtly. By establishing what counts as adequate description, explanation, and social response in the wake of disaster. By establishing how the past should be encountered (2001: 7).

In a long footnote, Fortun offers several theoretical formulations of the 'future anterior', beginning with Derrida and including Foucault, Canguilhem and Lacan. At the end of this note, she states, 'The future anterior is where the future is worked out, now' (2001: 361, n2).

31 'HBCAC's Mapping Project chosen to present at the ESRI International Conference', at www.hbcac.org/mapping.html (accessed July 2005), 29.

32 Ibid.

As we have seen, the practice of mapping gradually became professionalized on Long Island, as scientists for the State and LIBCSP researchers carried out their own GIS mapping projects with little input from the communities they were mapping. Control over the production of map-based knowledge shifted to experts, as did the power to access and interpret the new GIS maps. These exclusions, combined with the failure of the LIBCSP to prove environmental causes of breast cancer, have led the HBCAC to see its mapping activities in a new light, and to reassert the legitimacy of activists' own knowledge practices regarding the possible link between breast cancer and environmental causes. By doing this, they are attempting to reclaim a right to participate in research processes, and how data are interpreted, represented and put to use. They recognize as well that the motives that generate research are complicated. Through their new public policy initiatives, they assert the urgency of environmental change, and reject both the scientific standard of 'proof of causation' and the notion that scientifically generated evidence is needed to legitimate their claims and demands for action.

The practices of the HBCAC are an echo of earlier practices of breast cancer on Long Island. In order to understand 'breast cancer on Long Island' in all its complexity, we must attempt to hear those echoes that reverberate from the past and into the future. In *The body multiple* (2002), Mol describes the complexity of atherosclerosis in primarily spatial terms; that is, atherosclerosis gets enacted across and between multiple domains. Her project privileges the spatial, and only suggests on occasion the ways that practices are also always temporal. Still, the shift from knowing to enacting is crucial to our analysis. When we look at the multiple practices that have led to the emergence and enactment of the complex object 'breast cancer on Long Island', we don't take the object as pre-existing our attempts to know it. We too are trying to map this complex object. By foregrounding practices of mapping and precaution, and mapping as itself a practice of precaution, we begin to see how that object has been made and unmade, and might yet be made anew.

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