

# Health Advocacy, Inc.

## How Pharmaceutical Funding Changed the Breast Cancer Movement

SHARON BATT



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Praise for *Health Advocacy, Inc.*

“This riveting history of the breast-cancer movement chronicles, analyzes, and evaluates the relationship between patient-advocacy organizations and the pharmaceutical industry. The author’s autoethnographic observations shine brilliantly, and the issues she raises should incite debate about the need for medical reform and new health policy.”

– **SERGIO SISMONDO**, professor of philosophy, Queen’s University and co-editor of *The Pharmaceutical Studies Reader*

“This is a powerful insider account, coupled with excellent scholarship, of Big Pharma’s doings in relation to the breast cancer movement. After reading this book, the only thing I wanted was more – more information on how this work applies to other countries and to other health advocacy movements. This is a vitally important book.”

– **EVELYNE DE LEEUW**, director of the Centre for Health Equity Training Research and Evaluation (CHETRE) at the University of New South Wales, Australia

“Sharon Batt, herself a breast cancer survivor, weaves the personal with the political to tell the story of how most of the breast cancer movement ended up in the arms of the pharmaceutical industry. Abandoned by the federal government as it increasingly adopted a set of neoliberal values, the patient breast cancer groups turned to the drug companies for funding, and in doing so lost their way.”

– **JOEL LEXCHIN**, MD, Professor Emeritus, Faculty of Health, York University and author of *Doctors in Denial: Why Big Pharma and the Canadian Medical Profession Are Too Close for Comfort*

“I recommend this book to anyone who wants to understand the government policy changes and the manipulations, conflicts of interest, and very human dynamics that undermined the integrity of the breast cancer patient/survivor movement and skewed patient advocacy towards pharmaceutical industry interests. Sharon Batt’s meticulous research lays bare the troubling dynamics of drug industry funding and explores better ways to protect women’s health.”

– **ANN SILVERSIDES**, award-winning health policy journalist and author of *AIDS Activist: Michael Lynch and the Politics of Community*

“Sharon Batt has given us a riveting account of how health advocacy in Canada became colonized by the pharmaceutical industry. As a leader in the breast cancer and women’s health movement, she provides a compassionate and scholarly overview of the moral and ethical dilemmas many health activists faced when Big Pharma came knocking at the door. *Health Advocacy, Inc.* describes the public policies that were behind these heart-wrenching debates on the front lines and provides a roadmap back to independence.”

– **COLLEEN FULLER**, cofounder and president, PharmaWatch Canada

“A searing indictment of industry subversion of ‘patient’ groups. Batt chronicles the rise of industry fronts and industry-influenced patient groups that arose in parallel with (and as a result of) the rise of neoliberalism. She demonstrates how the same tools employed by industry to influence doctors are used to influence key patient groups in ways that patients may not recognize. Required reading for all lay groups tempted by industry money.”

– **JEANNE LENZER**, associate editor, *British Medical Journal*, and author of *The Danger within Us: America’s Untested, Unregulated Medical Device Industry and One Man’s Battle to Survive It* (forthcoming)

“As a public intellectual whose work spans the worlds of journalism, the women’s movement, breast cancer advocacy, and the social studies of medicine, Sharon Batt provides a nuanced analysis of the vexing problem of political advocacy and industry funding. This book has important implications not only for health policy and patient advocacy but also for the broader political conversation about neoliberalism, democracy, social movements, and social fairness.”

– **DAVID J. HESS**, professor of sociology, Vanderbilt University, and author of *Undone Science: Social Movements, Mobilized Publics, and Industrial Transitions*

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## Introduction

### THE SECRET WAR AMONG PATIENT GROUPS

*There's always been a huge war between people within the community, between those who accept pharma funding – as if it were black and white, you know, the “pharma-takers” – and the sanctimonious ones on the other side who feel they've never been tarnished by that conflict.*

– BETH KAPUSTA, CANCER ACTIVIST AND FORMER CANCER PATIENT

Few who know the patient advocacy community in Canada would deny that two hostile camps are a long-standing reality. This was not always the case, though the beginnings of the “huge war” Beth refers to are now lost in time. One aim of this book is to reconstitute the process of division as it played out in one segment of the community that speaks for patients: that of grassroots breast cancer groups in Canada. This story is worth telling in its own right. However, the narrative has wider resonance – beyond the breast cancer movement, beyond Canada, and even beyond patient activism. In Canada and the United Kingdom, scholars and health activists have documented splits in various patient communities over pharma funding – funding from the pharmaceutical industry. Activists in the breast cancer movement in the United States and Germany have described similar ruptures. In each case, one patient group decided not to accept funds from the pharmaceutical industry and broke with the larger community, in which the practice had become prevalent. Among patient organizations representing different diseases in Ireland, in France, and in the United

States, researchers have documented varying practices in relation to the pharmaceutical industry. These accounts hint at painful internal struggles but do not depict the process of contestation that took place over time. This book does.<sup>1</sup>

One may ask, why go there? Struggles within social movements are sometimes seen as tedious exercises in ideological hairsplitting, or the result of petty personality conflicts. When the individuals involved are sick – sometimes terminally – the divisions may seem all the more bewildering. When I was active in the breast cancer movement in the 1990s, exasperated onlookers would sometimes say, “Why can’t everybody just get along? You should all be fighting together, against breast cancer!” One assumption underlying this book is that the “pharma fights” within patients’ movements matter a great deal and that they have not been given their due. Divisions within movements signify a struggle among members to define a reality that is central to their world; deconstructing the struggle reveals how social groups create and defend competing knowledge systems. In the case of patient organizations, the struggle is over what meanings we assign to drugs and drug companies, and to the health and regulatory systems that control access to therapeutic technologies.

Understanding these struggles in patient groups matters, because in many democracies, including Canada, patients are now important policy actors. In the 1980s, both in Canada and in the United States, HIV/AIDS activism expanded the boundaries of health activism to include political action by patients. AIDS activists argued that patients have an “embodied knowledge,” derived from their first-hand experience of their illness as it affects their everyday lives.<sup>2</sup> Health policy makers and drug regulators began to take the patients’ perspective more seriously, acknowledging patients as interested parties in research and policy decisions. Patient advocacy groups have proliferated, and their views are solicited, even mandated, at many levels of health governance. The rise of patient groups is thus politically important and would seem to count as a democratic gain, giving voice to previously silent, powerless constituencies of patients. But if groups within the patient community deem their differences significant enough to warrant waging internecine wars, anyone concerned about health policy should ask, what is at stake here? A related question is whether partnerships between pharmaceutical companies and patient

organizations have contributed to a more democratic, participatory system of science governance.

Within the physician community, a similar tension over pharma funding has been examined for decades. Should physicians accept industry-funded trips to exotic places to attend educational talks? Should they accept big pharma's free meals? Is it okay to use pens bearing company logos? What about free samples from drug sales reps, to give to indigent patients? Physicians disagree on the answers, sometimes bitterly so. Although the debates about conflicts of interest in medicine are not yet resolved, they clearly matter. If corporate largesse encourages physicians to prescribe drugs when they are not appropriate, or to perform unnecessary medical procedures, the potential for harm is obvious. Quite apart from whether pharma funding influences the practice of medicine, the profession depends on the trust of patients, whose vulnerability magnifies the physician's power; on these grounds, physician and ethicist Howard Brody has argued, the potential of influence alone is reason enough for physicians to refuse industry funds or gifts. The debates within the patient community over pharma funding have had less exposure, but the parallels are striking.<sup>3</sup>

Also striking in their similarity are debates about corporate funding within other segments of the nonprofit, voluntary, or NGO (nongovernmental organization) sector. Since the early 1990s, alliances between activist groups and multinational corporations have proliferated. The World Wildlife Fund now accepts funding from Coca-Cola; the International Youth Foundation receives funds from Microsoft and Nike, among others; Oxfam has agreements with Starbucks and Unilever. This transformation has caused turmoil within NGO communities. Long-time Greenpeace leader Patrick Moore left that organization in 1986 and openly criticized it, "not for being corporatized, but for not working closely enough with corporations." On the other hand, when the Sierra Club accepted millions in donations from the gigantic gas driller and pro-fracking corporation Chesapeake Energy, outraged environmental activist, biologist, and author Sandra Steingraber said it was as if "anti-Fascist partisans had discovered that Churchill was actually in cahoots with the Axis forces."<sup>4</sup>

These concomitant conflicts suggest common underlying causes, and the broad strokes of my analysis at the national and international levels

coincide with that of others who have explored the sociopolitical transformations of the past three decades. In wealthy democracies, including Canada, neoliberal governance regimes have reshaped state policies and profoundly altered the funding practices that characterized civil society organizations in the welfare state era preceding it. These macro-level changes in funding practices have in turn changed the understanding of concepts like advocacy and the social good. This transition has done much to shape the group or meso-level politics within the patients' movement, including competing advocacy agendas regarding pharmaceutical policies: What do patients need, anyway? And what policies will best address these needs? Groups negotiate these questions and goals within a broader political framework that has shifted over the past three decades, and that continues to evolve.

I look at the macro-level forces through the lens of breast cancer patient advocacy groups in Canada as they formed, gained recognition, grew, and diversified over time. At the heart of the narrative is an examination of how groups grappled with an ethical question: Can they accept pharma funding and still advocate for drug treatment policies that serve the best interests of patients? We'll look at how members of the community with different perspectives developed competing ethical arguments, how one argument achieved precedence over another, and how the outcome shapes understandings about drugs. Also explored are what power relationships are at play as two factions struggle to each have its perspective seen as true, and how shifts in national and transnational policies influenced debates within the groups.

### **What Are PHANGOs and Why Do They Matter?**

My research draws on extensive research within Canada's breast cancer community for two decades beginning in 1988 and documents the process by which pharma funding became the norm within the patient advocacy community. Tying the existence of these alliances to the politics of neoliberalism and its culture of partnership, I coined the word "PHANGO," meaning pharma-funded NGO, and referencing a vocabulary that characterizes NGOs according to their relationships with sponsoring partners – for example, BONGOs, DONGOs, GONGOs, QUANGOs, and BINGOs.<sup>5</sup> Anthropologist William Fisher maintains that this proliferation of NGO

acronyms can be counterproductive, since their creation and use is inconsistent and “often derives from a narrow objective on the part of the analyst.” Although this criticism could be made of the term “PHANGO,” I believe that terms designating a collaborative arrangement between a class of NGOs and a financial sponsor have value.<sup>6</sup>

First, I wanted to avoid the term “astroturf group,” which references the fake-grass product and is used pejoratively to refer to groups with covert industry funding that present themselves as grassroots organizations while lobbying to promote corporate interests. Although the term is sometimes applied to any patient group that accepts pharma funding, I agree with Steven Epstein that the suggestion of a front group is best reserved for “one end of a continuum,” that is, pharma-funded groups created by pharmaceutical companies to promote their products or gain support for regulatory approval.<sup>7</sup> My research in Canada’s breast cancer community depicts a more complicated reality. In some groups, members actively debate the issue of pharma funding, with the weight of opinion shifting back and forth over time. In others, ambivalence is a constant: pharma funding is deemed acceptable under some circumstances but not others, and offers are continually negotiated. A few groups were rumoured in the community to be pharmaceutical-industry creations, but the organizations’ leaders told a different story, and I was not able to determine the truth. Taking this variability into account, I intend the term “PHANGO” to be descriptive rather than pejorative, denoting the full range of groups that have one or more pharma partners but which may vary widely in their terms of engagement.<sup>8</sup>

This use is in keeping with Fisher’s admonition that “what is at issue is not ... whether a specific association is or isn’t an NGO, a QUANGO, a CONGO ... but what happens in specific places and at specific times.”<sup>9</sup> He argues in favour of ethnographic studies that highlight the rich diversity of NGOs, depicting them as arenas that internalize battles from the larger society. In coining the term “PHANGO,” with its allusion to the tango, I mean to capture this spirit of continual improvisation and struggle to adapt to local conditions, as well as the process of ongoing collaboration with a partner, which may be tinged with antagonism.

As well, by using the terms “patients’ movement” and “breast cancer movement,” I mean to exclude the large, established disease charities, such

as (in Canada) the Canadian Cancer Society and the Canadian Breast Cancer Foundation. Both are primarily fundraising organizations that distribute funds to researchers and, in the case of the Cancer Society, provide professionally led and volunteer services. Although their structures may include patients as staff or volunteers, they are not self-help or advocacy organizations run largely by patients (the two charities merged in late 2016).

The alliances between patient organizations and corporations that are my focus here are specifically those with pharmaceutical companies – not, for example, the cause marketing alliances that many patient groups have formed with corporations. Cause marketing is a type of marketing in which a company links one of its consumer products to a popular charitable cause.<sup>10</sup> To gain market share and burnish its image, the company gives the organization in question a portion of the proceeds from sales, in exchange for attaching the organization's name or logo to the product. Cause marketing has linked breast cancer charities to spring water, yogurt, jeans, makeup, kitchenware, cars, and even guns. If there's a common thread in this list, it's that the products have no obvious relationship to the disease. A company that engages in cause marketing flaunts the alliance because it wants to forge a connection, in the public's mind, between its product and the cause. Drugs, by contrast, have everything to do with disease. Pharmaceutical company alliances with patient organizations therefore raise questions, some of them legal, about marketing. Pharmaceutical companies may prefer to fly under the radar when supporting patient groups because, unlike ordinary consumer products, drugs are highly regulated. Their marketing and use is controlled because they can harm health as well as improve it. Patient-group advocacy with pharmaceutical company sponsors thus have the potential to distort policies that have been put in place to protect the public health. This concern is at the heart of my investigation.

### **Patient Advocacy Groups, Science Research, and Health Policy**

The interdisciplinary field of science and technology studies (STS), in which my research is situated, is the study of how social actors affect the creation and interpretation of scientific knowledge. Recognizing that

science is a human endeavour means science is never neutral but is affected by scientists' values, politics, and agendas. STS research goes beneath the mask of neutrality that science sometimes wears to show the socially constructed aspects of science and science policy. A critical STS inquiry assumes that scientific discovery should contribute to the public good, and analyzes science policy, governance, and funding with the aim of advancing equality and other social justice goals.<sup>11</sup>

STS researchers study patient groups and health movements because the groups bring lay expertise to bear to politically shape the scientific agenda, and because the organizations have an inherent interest in the science and technologies that are applied to predicting, diagnosing, and treating disease, says Steven Epstein, whose ethnography of the AIDS movement in the United States is the bellwether STS analysis of a patients' movement. Interest in social movements and activist groups is relatively recent in STS literature. Early incarnations of STS focused on scientists and their laboratories. Critical STS provides a powerful lens for examining social justice issues in health movement and patient groups, yet researchers in the field have been slow to problematize the pharma funding of these groups, or the broader issue of commercialization in science.<sup>12</sup> Although many researchers have acknowledged the issue of corporate ties in health-related and patient organizations, their interest in challenges to dominant cultural authorities has led some to selectively study the more radical health organizations. The result is a tendency to conceptualize the groups as social movement organizations when in fact many – such as those with corporate ties – may be “contributing to the intensification of biomedicine’s authority and further widening its jurisdiction.”<sup>13</sup> Health activism, then, can bring about change that is progressive or regressive.<sup>14</sup>

Perhaps more intriguing, a patients' movement can do both at once. The AIDS movement in the United States is, arguably, an example of the latter. In his 1996 *Impure Science: AIDS, Activism and the Politics of Knowledge*, Steven Epstein documents how AIDS activist groups changed the practice of medical science by demanding changes in the clinical trials process used to test the safety and efficacy of HIV/AIDS medications. With a cry of “Drugs into bodies,” they contested the ethics of placebo-controlled trials that required desperately ill patients participating in trials of new

medications to risk being randomly assigned to the “no drug” arm of a trial. There is little doubt that pressure from the patient community accelerated the pace of research and dramatically slowed the pace of deaths, particularly in wealthy countries.<sup>15</sup>

The groups also altered American drug policy by challenging the American drug regulator, the Food and Drug Administration (FDA), to approve new drugs for HIV/AIDS more quickly, shifting the agency’s priority from safety to access. Here, the cost-benefit balance of patient activism is more ambiguous. The macro-level political economy environment in which American AIDS activist groups functioned remains in the background in Epstein’s treatment; however, the rise of AIDS activism in the 1980s coincided with the rise of neoliberal politics. Activists were aware that some of their demands for regulatory change meshed comfortably with the goals of the conservative administration of Ronald Reagan, as the following passage makes clear:<sup>16</sup>

The FDA was killing the drug companies and preventing useful products from getting to market, the [conservative] argument ran; the best solution would be to repeal the Kefauver-Harris amendment, which had granted the FDA the authority to assess the safety and efficacy of drugs. “Especially considering who was the president, we had concern” about adding fuel to the deregulatory movement, recalled David Barr of ACT UP/New York: “But it wasn’t enough concern that it would stop us from doing what we were doing.” Soon, an unlikely alliance had developed – usually tacit, but sometimes explicit – between AIDS treatment activists and conservatives, leaving consumer protection groups and treatment liberals on the other side.<sup>17</sup>

In highlighting the impact of AIDS activist groups on research and regulatory policy, Epstein’s study illustrates how actors with noncredentialed expertise can leverage their power to affect the practice of medical science and the regulation of medical technologies. This knowledge is not simply a less sophisticated grasp of the knowledge experts possess, but an epistemology that merits study in its own right. Medical anthropologists use the term “embodied knowledge” to characterize a type of experiential, lay knowledge based on the ways in which people experience

their bodies and make sense of a bodily state (well-being, health, illness) in their everyday lives. The term shifts the idea of understanding of a disease state away from expert knowledge to what is learned first-hand from the day-to-day experience of living with an illness. Embodied knowledge incorporates cultural variables: one's history, language, politics, and local (including scientific) knowledge. It may differ from, or align with, expert knowledge. STS theorizing addresses this embodied quality in its attention to the "intermingling of humans and non-humans;"<sup>18</sup> in the case of a drug, the nonhuman entity literally acts on and becomes one with the patient's body.<sup>19</sup>

HIV/AIDS activism enlarged the critique of both the pharmaceutical industry and the drug regulatory agencies while adding a new dimension to health activism: collective pressure on researchers to target their research to particular diseases, and on drug regulators to provide access to novel treatments still in the pipeline. The first wave of the AIDS activist movement, which began in the United States in the early 1980s, combined demands for drugs with a strong critique of the pharmaceutical industry. More recently, analysts within the movement have voiced cautions about the potential of pharma funding to soften AIDS activism's critical edge.<sup>20</sup> Steven Epstein distinguishes between co-optation, in which "the radical potential of an activist critique is blunted or contained," and incorporation, when the insights of patient advocacy transform biomedical practice.<sup>21</sup> Co-optation is problematic, whereas incorporation is a sign of a movement's success, but the two processes may be hard to distinguish, as they can appear similar or may both be happening at the same time. As an ambiguous example of what might appear to be co-optation, Epstein cites the moderation of AIDS activists' political goals and methods over time, a change that he attributes in part to changes in the research trajectory and in part to activists' advances in their understanding of AIDS. In this case, he says, "blunt and accusatory terms such as 'cooptation' appear unhelpful." As if to illustrate the caution that activists' policy stances reflect a complicated trajectory of learning by multiple parties, in June 2015, two cofounders of the AIDS Treatment Action Group joined with former FDA commissioner David Kessler to oppose a new US bill, the 21st Century Cures Act, on the grounds that it could "substantially lower the standards for approval of many medical products, potentially placing patients at

unnecessary risk of injury or death.” Rapid access to new treatments was good for patients, the trio argued, only if it was restricted to serious or life-threatening diseases and paired with rigorous follow-up to ensure that the treatment actually improves patients’ lives.<sup>22</sup>

### **The Dual Nature of Drugs**

Epstein’s analysis points to the need to study movements over time and also implicitly raises the issue of gender politics. The early AIDS movement grew out of the largely male gay activist movement and bore the imprint of gay activism at the time, including confrontational tactics and relatively young, educated, white, middle-class, urban leaders. The women’s health movement, which dates to the 1960s, also had young, educated, white, middle-class leaders but a less confrontational political style and a different historical relationship to medical treatments. Women’s embodied knowledge included their central role in human reproduction, as well as their experiences as family caregivers in times of both sickness and health. Abby Wilkerson provides an especially thoughtful analysis of the contrasting attitudes toward drug regulation between feminist and gay male activists, based on the different ways the medical profession stigmatized each community. Whereas healthy women have often been prescribed drugs to make their bodies conform more to a male ideal, physicians and other health professionals were reluctant to treat patients with AIDS.<sup>23</sup>

Feminist scholars have documented a long history of women’s groups advocating for health and medical choices that are more holistic and inclusive than those based on a heterosexual, male-centred, biomedical model. The women’s health activists who were part of the post-1960s feminist movement began to analyze structural reasons for women’s exploitation, including violence against women, the medicalization of their bodies, the denigration of their caregiving roles, and the control pharmaceutical companies exercised over women’s bodies and emotional states. This control spawned an antagonism toward the pharmaceutical industry, but the anger was not based – as it was in the early AIDS movement – on a belief that their plight merited more attention from the medical establishment. Rather, women were outraged by pharmaceutical company ads that reinforced demeaning stereotypes of women and by the harm they suffered from the misuse and overuse of drugs to treat normal conditions (like

pregnancy), or states that had social roots (like depression). In short, “Drugs into bodies” was far from being the cry of the women’s health movement; where drugs were concerned, women’s health activists wanted effective health protection laws, and they looked to government agencies, like the FDA and (in Canada) the Health Protection Branch of the federal Department of Health, to provide them.<sup>24</sup>

The contrasting view of drugs in the early AIDS movement and the women’s health movement is no anomalous fluke. Aside from the radically different ways in which medicine treated healthy women and gay men with AIDS – overtreating the former and shunning the latter – drugs, by their nature, evoke both desire and fear: they can cure and they can poison.

Pharmaceutical drugs and their antecedents, such as herbal remedies, have long been recognized as potentially useful, but also dangerous, interventions. *Pharmakon*, the Greek word for drug, has multiple other meanings, from remedy and poison to magic, spell, and charm. Jacques Derrida, in an extended reflection on the term and its contradictory meanings, argues against seeking a stable essence in the inherently ambivalent and oppositional. Scholars of feminism’s third wave have cautioned against an oversimplified critique of pharmaceuticals in women’s health, arguing that women respond to medicalization in ambivalent ways, negotiating rather than rejecting medical procedures and pragmatically accepting medical relief from pain, infertility, or premature death. Critical analyses of patient groups thus need to capture the tension of appeal versus risk and exploitation inherent in our relationship to technologies, including drugs. When it comes to medicalization, women have the agency to reflect on and choose among available discourses and practices and are able to adapt them to their own needs and values.<sup>25</sup>

In the AIDS movement, this tension and capacity for adaptive response was evident in the activists’ response to azidothymidine (AZT), the first of the AIDS drugs that “did something” to the immune systems of AIDS patients in clinical trials but also caused severe adverse effects in some patients, including anemia, nausea, and headaches.<sup>26</sup> Although activists recognized the drug’s limitations, they initially saw AZT as an early rung on a ladder that would eventually lead to a cure – hence the “drugs into bodies” strategy, adopted in the hope of keeping patients alive until a better drug came along. By the early 1990s, however, AZT was still the front-line

therapy, despite being marginally effective and disliked by patients, and activists began to shift strategy gears: rather than access for the patients of today, they wanted answers – even if they themselves were not the beneficiaries; they wanted good science that would someday lead to an effective therapy or cure.<sup>27</sup>

The double-edged nature of drugs has an economic aspect also. Historically, apothecaries (the predecessors of today's pharmacists), as well as governments, have sometimes adopted the stance of protector of people's health, regulating the prices of drugs and the truth claims of those who sell them; in other periods, officials allowed vendors to exploit the seemingly magical quality of drugs as a source of easy profits. Today's neoliberal regimes define pharmaceuticals as commodities vital to the expansion of knowledge-based economies and, to this end, Canada and other states have revised regulatory controls on the pharmaceutical industry to facilitate international trade in these products. Some analysts of pharmaceutical policy believe neoliberal governments have gone too far in recalibrating the regulatory balance, allowing economic interests to trump its responsibility to protect the public health. I situate the PHANGO within the morally charged debates about these regulatory changes.<sup>28</sup>

### **The Neoliberal Connection**

Definitions of neoliberalism abound, to the point where some scholars argue that the term has lost all analytic usefulness. I disagree, siding with those who believe the neoliberal paradigm shapes contemporary political and economic life and can't be ignored; furthermore, despite various understandings of the term, agreement exists on neoliberalism's central philosophical underpinnings: that markets are valued in themselves and all human action should be directed toward intensifying and expanding them. To ground my analysis, I adopt David Hess's definition of neoliberalism as "both public policies and economic thought that have guided a transition in many of the world's economies toward the liberalization of financial and other markets, the privatization of public enterprises, and the retrenchment of government commitments to social programs."<sup>29</sup> Canada's economy has undergone such a transition, and the realignments in public policy are central to my narrative in three domains: the health care system, the regulation of pharmaceuticals, and the role of civil society.

A few caveats are in order, however, to address the concerns of skeptics. First, the expansion of markets into nonmarket domains does not proceed in a single predictable pattern. Social geographers Kevin Ward and Kim England suggest thinking about state restructuring as a process, an evolution that unfolds unevenly and dynamically under different conditions. Ongoing struggles, including the resistance strategies of some actors (e.g., unions, public intellectuals, activists), contribute to making the path of neoliberalization unpredictable. Thus, an expansion in state funding of health care (which Canada experienced during the period under study) may be consistent with a neoliberal agenda. A critical question is who benefits from this spending? If, for example, rising public spending on health care benefits corporate interests (e.g., the pharmaceutical industry) and certain elite groups (e.g., affluent citizens, specialist physicians), without improving the overall health of Canadians, public spending is arguably serving the market while eroding the system's social justice goals.<sup>30</sup>

Recognizing the influence of neoliberalism on national and global economies and public policies, Kelly Moore and colleagues call for explorations that identify new patterns in the interrelationships among industry, science, and social movements. For these scholars, conflict is important. Of particular interest to an understanding of neoliberalism are conflicts arising from countervailing pressures, “from industry and the ‘right hand’ of the state on one side ... and from civil society and the ‘left hand’ of the state on the other side.”<sup>31</sup> The French sociologist Pierre Bourdieu's metaphor of the state's right and left hands recognizes that governments have two broad types of obligations that are sometimes in conflict: to support economic interests, via such agencies as the Ministry of Finance and the banks, and to provide citizens with needed protections and services, the task of ministries like defence, health, and education that must spend money to achieve their goals.<sup>32</sup> For Bourdieu, neoliberalism was an “infernal machine,” bent on the destruction of all the collective institutions capable of counteracting its effects; the institutions in jeopardy were primarily those of “the state, repository of all the universal ideas associated with the idea of the *public*.” The only hope he saw for the construction of a new social order oriented to solidarities and social values was for individuals and groups with a tradition of civil and public service to resist the vision of accountants.<sup>33</sup>

If civil society groups exist to protect and provide services that advance the public good and are available to all, they will tend to be aligned with the state's "left hand," but under neoliberal governments, the numbers of such groups advocating for pharmaceutical policy in the public interest have been dwindling, political theorist Hans Löfgren concluded in 2004. Löfgren studied the changing influence of consumer and patient advocacy groups in pharmaceutical policy in Australia and globally. He found contrasting perspectives among groups over pharma funding and concluded that groups today play contradictory roles in the pharmaceutical policy domain. Depending on their mandates, some resemble the critical social movements of the 1960s and 1970s, which questioned established experts and powerful institutions, but many others may be fully incorporated into dominant power structures and exhibit characteristics of corporations, "with chief executive officers, large budgets and business plans."<sup>34</sup>

Löfgren notes the usefulness of analyses that compare neoliberal governance models with those that preceded them, in which bargaining relationships between capital, labour, the state, and sectorial interests were kept at arm's length. Neoliberal governance, by contrast, is premised on the notion of partnerships between actors who span a wider range, and relationships are no longer arm's length. The emergence of pharma-funded patient groups reflects this political evolution. Löfgren concludes that Australia, like other industrially developed countries, still accepts government regulation of pharmaceuticals as necessary to the market economy, but the government's role is no longer to ensure public health above all; rather, governments strive to retain social acceptability while coordinating and facilitating international market exchange. To achieve this, neoliberal governments manage pharmaceutical policy by orchestrating negotiations among large numbers of public and private "stakeholders," organized in complex networks of partnerships. (The term "stakeholder," used to denote anyone who is affected by a course of action, is itself neoliberal terminology, writes Joshua Sharfstein, a physician and former commissioner at the FDA. In a critique of the term's proliferation in the health policy world, Sharfstein notes that the term's more common use denotes someone with a financial stake in the success of an enterprise. In health policy, those referred to as stakeholders – such as pharmaceutical companies – often do have a financial stake in discussions, but the interests of these parties can

be at odds with good health policy, which advances public health while containing costs. Referring to everyone around the table as a stakeholder shrouds the deliberations in a dense fog, Sharfstein argues, obscuring differences in goals that should be made visible.<sup>35</sup> Following Sharfstein, I do not identify patients or patient organizations as stakeholders, though I do quote texts and cite individuals who use the term this way.)

Patient and other health sector advocacy groups play a prominent role in certain negotiating networks because a neoliberal regime awards various societal sectors a claim to political participation based on their different stakes in the uncertainties of the globalized world – what sociologists Ulrich Beck and Anthony Giddens have termed the “risk society.”<sup>36</sup> Patient groups are awarded participant status in the drug policy arena because of their obvious stake in the availability, effectiveness, and safety of pharmaceuticals. In this capacity, part of their role is to articulate the amount of risk they consider acceptable in drug treatments. Historically, says Löfgren, Australian health and patient advocacy groups were allied with the Health Department on such regulatory matters as equity, accessibility, rational drug policy, and appropriate prescribing. Over the decade prior to his study, he concludes, the pharmaceutical industry had purposefully weakened the alliances with the Health Department through dialogue, collaborative marketing, and sponsorships.

As Löfgren’s analysis implies, neoliberal regimes alter the national frameworks in which advocacy groups function and, some have argued, redefine the meaning of advocacy. Canadian feminist scholars have documented the ways in which neoliberal discourses and funding policies in Canada changed the political environment to weaken conflictual group activism and privilege a depoliticized, consumerist, noncontentious individual engagement in the political system. Having stripped away their advocacy role, governments rebranded civil society groups as the “voluntary sector.” Lawyers Judy Fudge and Brenda Cossman propose that neoliberal policies encouraging alliances between health charities and drug companies set back women’s equity struggles in the area of health. Governments in the new order now rely on health charities to provide their members with services that once were the domain of the health care system, so are loath to discourage these alliances, they say. Fudge and Cossman note that health charities now have extensive websites that carry useful

information on topics like self-care and family support, which alleviates pressures on the health care system. At the same time, the sites have disease-specific information, including drug information, which will probably increase pressure on the health budget by promoting new, expensive, and not necessarily better drugs. Although nonprofit organizations are becoming larger, richer, more powerful, and more “corporate,” Fudge and Cossman argue that they are losing their autonomy via strings to corporations.<sup>37</sup>

Patient-driven organizations and websites are evidence of what some theorists have termed “biological citizenship” or “biosociality,” a new type of identity politics in which individuals with the same disease form organizations and assert rights based on patient status. These claims can arise from health harms, as when the post-Chernobyl citizens of the Ukraine mobilized to claim compensation for adverse health effects they suffered from radiation exposure; or they can be based on the perceived benefits of new health technologies, such as genetic tests and treatments. Paul Rabinow, Nicholas Rose, and colleagues argue that the new genetic discoveries arising from the Human Genome Project have led to the creation of groups whose members are susceptible to the same disease; they are, in Michel Foucault’s terminology, a new episteme: sites of new knowledges and powers, based on genomics. Rabinow calls this new type of identity, formed in response to genetic technologies, “biosociality.”<sup>38</sup>

For Rabinow, AIDS activism provided a model in which patient organizations could keep scientists honest by reminding them that the point of medical research is to alleviate suffering. By engaging scientists in ongoing dialogue about their work, such groups could counter the self-interested, sometimes arrogant, culture of science, which in the past had led to inhumane experiments. The ascendance of neoliberal regimes had replaced ruling elites whose values were shaped by humanism with managers who valued neither science nor humanism, Rabinow reasoned, so checks on science were particularly needed. Building on Rabinow’s analysis, Nicholas Rose and Carlos Novas conducted case studies of partnerships among patient groups, biotech companies, and biomedical researchers. They propose the concept of biocitizenship to theorize innovative citizenship projects where patients and their allies sometimes lead in setting ethical standards and pushing scientific boundaries.<sup>39</sup>

These same scholars and others agree that the diversity in patient-centred groups calls for empirical research and theorizing to lend greater nuance to concepts like biocitizenship. Medical anthropologist Margaret Lock, for example, studied the support group networks that developed after Alzheimer's disease was named as a heritable condition in the late 1970s. She found that discussions at the meetings, attended mainly by family members involved in care giving, paid little attention to whether genes are implicated in the condition and instead focused overwhelmingly on practical coping strategies for caregivers. And in a theoretical analysis, Alexandra Plows and Paula Boddington argue that the "bio" prefix in "biocitizenship" risks obscuring debates that require urgent attention, including those between groups that mobilize to contest corporate power in the health field and those that support a gene-focused research and policy agenda while using pharma funding to mobilize. In a similar vein, Thomas Lemke, in a 2015 assessment of biosociality and its limitations, observes, "Power relations have not been adequately addressed in the analysis of biosocial communities."<sup>40</sup> He critiques the bulk of the theorizing and research that has come out of the biosociality concept as one-sided, giving too much weight to biomedical knowledge as a force constituting the identities of individuals and their organizations. The converse is also true, he argues: the hopes and needs of patients, and the visions and interests of scientific experts, simultaneously shape the conduct, interpretation, and application of medical research.<sup>41</sup>

Recognizing the diversity among patient groups, many researchers have developed classificatory systems to organize the types of organizations and their salient features, a practice that itself has led to a confusing array of typologies. Based on a 2008 review of the literature on patient groups and health movements, Steven Epstein identifies six important questions that underlie the diversity of these groups, suggesting that researchers should recognize that their research question will inevitably "chop up the universe of cases in a distinctive way."<sup>42</sup> Among Epstein's six dimensions, my research highlights primarily the groups' degree of independence from corporations, state agencies, or professional associations. A secondary question from Epstein's list that differentiated the groups is their relationship to medicalization: some groups seek medical recognition for a condition, whereas others contest or resist medical interventions.<sup>43</sup>

### **Pharma Funding of Patient Groups**

Since 2000, the phenomenon of patient groups with pharma funding has attracted the attention of health policy makers, becoming a theme in the scholarly literature on health policy literature and medical ethics.<sup>44</sup> Nonetheless, the move to industry funding and the reasons for it have not been analyzed in detail. Most research on the groups consists of surveys, which establish the PHANGO phenomenon as real and widespread, and studies of websites and other public documents, which point to the covert nature of the funding and argue that both the industry and groups have a public responsibility to open their relationships to public scrutiny. Localized case studies of pharma funding within patient groups, which are less common, have shown that in Ireland, Finland, France, and the United Kingdom, groups differ among themselves in the stance they adopt to accepting industry funds.<sup>45</sup>

At a 2006 pan-European workshop, health researchers from ten countries came together to discuss health consumer and patient organizations in Europe and identified funding by drug companies as a major issue.<sup>46</sup> In most countries, researchers reported, groups had moved from self-help to greater political awareness and lobbying, but their financial and human resources were often limited. Their impact on policy was only apparent if powerful interests supported the organizations: the medical profession, state agencies, or the pharmaceutical industry. Workshop delegates worried (but had not demonstrated) that dependence on pharmaceutical companies increased the likelihood that the organizations would support the industry's interests, but recognized that funding from professional organizations and government could also compromise independence. These researchers considered the internal workings of health consumer and patient organizations to be inadequately documented but expressed concerns that some were not democratic or representative – no small details, since the participation of lay participants in decision making is meant to promote greater democratization in science.

In Canada, two physicians writing in Canada's medical journal of record made the claim in 2010 that organized political activism by patient organizations contributes to the misallocation of health resources because of inequalities in representation among disease groups. Paul Hébert and Matthew Stanbrook wrote: "Although federal leaders elsewhere have

galvanized their citizens to develop national evidence-based health care institutions ... Canada's parliamentarians issue occasional impassioned pleas on behalf of specific patient groups fortunate enough to make their concerns appear politically expedient."<sup>47</sup> Canadian medical anthropologist Janice Graham notes the potential for groups comprising patients or their family members to publicly portray their members as "caring humanitarians" pitted against "cold guardians of the public purse" as they demand that a new, untested therapy be added to a drug formulary. Graham continues: "So we are prescribing and funding drugs, despite the lack of strong, publicly sponsored best-evidence of efficacy, to satisfy family (and, one presumes, clinician and industry) demands."<sup>48</sup>

Social groups use discourses – words, arguments, claims, visuals, and other modes of communication – to construct their social worlds, or understandings of reality. Discourses about pharma funding of patient groups thus provide windows into the way these contrasting social worlds are constructed. In 2007, the *British Medical Journal (BMJ)* invited pro and con commentaries on the question of whether patient groups should accept money from drug companies. Alastair Kent, director of the Genetic Interest Group (now Genetic Alliance UK) in London, England, argued that they should, because money from the pharmaceutical and biotech industries allows groups, including his own, to provide better services and support for the individuals and families they represent. There is nothing inherently wrong with pharma funding, he said, provided that "the source is acknowledged and there are no hidden strings." Besides, he continued, public money and grants from charitable foundations cannot be assumed to be strings-free either, as "no person or group will be overly keen to support a campaigning organization if they think that their money will be used to 'buy a stick to beat them with.'"<sup>49</sup>

In contrast, Barbara Mintzes, an epidemiologist at the University of British Columbia, wrote that funding to patient groups from industries that sell products to treat their illnesses involves an inherent conflict that compromises the groups' ability to provide impartial information and to speak on behalf of people who are ill. Mintzes cites three dangers to patients: disguised product promotion funnelled through a seemingly impartial party, confusion between the interests of the group and the corporate sponsor, and inadequate representation for patients when those interests

diverge.<sup>50</sup> Although she welcomed steps to make funding arrangements more transparent, Mintzes contends that the problems remain: groups are reluctant to discuss safety concerns about a drug if they have received money from the company that makes it; similarly, the groups are likely to side with a sponsoring company in policy disputes over such issues as which drugs to insure. The evidence points to even small donations compromising a group's impartiality, said Mintzes, and industry-funded groups eventually may lose public trust.

### **Research Methodology and Its Underlying Rationale**

This detailed examination of a national patients' movement's involvement with the pharmaceutical industry over an extended period is the first I know of. I use interviews, direct observation, and detailed analysis of documents from multiple sources to provide a fine-grained description with three main threads, each of which changes colour and texture over time: the development of PHANGO culture as seen from inside a movement, the effects of macro-level changes on local organizations, and the socially constructed meanings of medications.

The historical tracking of groups has two main purposes. First, only an analysis over time can answer questions about whether and how funding from pharmaceutical companies co-opts patient groups, since co-optation implies a process in which the donor corporations increase their influence within the groups in conjunction with funding. Second, the political-economic culture within patient organizations is shaped in no small measure by constantly changing policy decisions made at the macro-political level; these interactions can only be captured in a study that tracks their evolution.<sup>51</sup>

To expand on the first point, a critical question is whether, under the influence of a corporate donor, the group endorses positions on pharmaceuticals and related policies that are counter to its members' interests. As Epstein points out, a group's position may appear to move closer to that of industry for reasons unrelated to co-optation.<sup>52</sup> A similar logic underlies debates about the significance of "professionalization" in activist movements. In a common trajectory, groups outgrow their volunteer roots and adopt a more professionalized model with paid staff, secure funding, and recognition by establishment actors like physicians, health researchers,

and decision makers in government. A rise in professionalism is sometimes viewed as inimical to grassroots activism, but Robert Kleidman, a sociologist who studies social movements, contests this claim as overly simplistic. Categorizing a group as either grassroots or professional assumes that professionalization moves the group's perception of issues closer to that of professionals and renders the group less able to represent the interests and knowledge of people at the grassroots. But, Kleidman objects, simply observing that the structure of a grassroots group (or movement) has become professionalized is insufficient evidence to conclude that the group has abandoned its commitment to grassroots objectives. Paid staff, for example, can be used to train local activists in radical tactics, making the organization more challenging to the status quo, not less. Kleidman urges social theorists to develop models that consider not only resources and political opportunities but also the values and strategies of movement professionals.<sup>53</sup>

Orla O'Donovan, who conducted research on pharma funding of patient groups in Ireland, rejects a straightforward astroturf/authentic dualism, for reasons similar to Kleidman's. Pharmaceutical companies have successfully defined themselves as a philanthropic force and as rightful players in Irish health activism, but research has yet to demonstrate that these ties have eroded the mandates of these organizations from contesting the status quo to accepting dominant structures and discourses. She poses the possibility that health advocacy organizations can both disturb orthodox understandings of health, illness, and patienthood while reinforcing pharma-centric health discourses and the commodification of health activism.<sup>54</sup>

On the second rationale for studying the groups over time, I wanted to illuminate the ways in which changes in macro-level policies affect advocacy groups concerned about drug regulation. To this end, my research spans three decades in which Canada underwent a radical transition, from welfare state to a nation in which governance structures were realigned to reflect the trade-based assumptions of neoliberalism and neoconservatism. Patient-centred health advocacy began its ascent on the cusp of this political restructuring: the high-profile AIDS groups began organizing in the mid- to late 1980s, and breast cancer groups soon followed, in the early 1990s. Many other disease-specific organizations have modelled themselves

on these examples. Researchers in other sectors have documented how policy shifts reverberated through well-established civil society movements, such as services for children and families and the environmental movement; I ask whether groups within patients' movements felt their effects as well, and if so, how.<sup>55</sup>

By shifting attention from the work of scientists to that of patients, who are among the main users of scientific discoveries, I highlight unequal relationships of knowledge and power. How do patient groups understand the health technologies (especially drugs) that are developed in their name? How do they weigh social justice in the distribution and application of these technologies? And how do alliances with pharmaceutical companies affect these knowledge/power/justice equations – if they do at all?<sup>56</sup>

I made breast cancer groups in Canada the focus of my research in part because they constitute an important social movement in themselves, and one that other patient communities look to as a model. The rapid emergence and growth of the breast cancer movement is arguably the most remarkable example of health activism in the 1990s; yet, despite many fine scholarly investigations of this phenomenon, the theme of pharma funding in that movement's evolution remains largely overlooked. Also critical to my research, the evolution of breast cancer groups spans several decades – a necessary requirement for studying change over time. The scope of my research includes a period of overlap between the breast cancer movement and the women's health movement that preceded it by two decades. The two health movements bleed into one another – though not always harmoniously – and some individuals engaged in the earlier movement became leaders in the later one.<sup>57</sup>

From my participation in the breast cancer movement in the 1990s, I knew that the issue of pharma funding had been debated within many of the groups, and that these discourses developed in tandem with the debates about various treatment regimens these same companies were bringing to market. To understand the interrelationships between groups and drug treatment debates, I tracked the “social lives” of breast cancer drug treatments over the same twenty-year period. The concept of drugs having social lives recognizes that a drug acquires social meanings as it passes through its life cycle – the trajectory from development to actual use to eventual obsolescence.<sup>58</sup> Our understanding of a drug derives only in part

from its objective qualities; a range of actors with varied values and vested interests add profoundly subjective meanings.

Drug companies understand this process well. Alastair Matheson, who worked for over a decade in communications in the pharmaceutical industry, explains that, during a drug's development, companies construct narratives that integrate scientific and marketing goals to shape scientific and medical knowledge about the new product. As the drug approaches market, the company often creates "key messages" that "describe the background area of medicine, why the drug is needed, how it benefits the patient, why it is superior to its competitors, and why it is cost-effective."<sup>59</sup> Patient groups comprise a relatively new addition to the array of social actors positioned to engage in this process of negotiated meaning making, which they can accomplish in a more politically effective way than individual patients.

I organize my narrative of the breast cancer movement's relationship with the pharmaceutical industry into three periods, each of which is defined by the practices, discourses, and struggles within the groups. Describing the phases of advocacy in a patients' movement this way highlights turning points at which the power relations shift and transform the relationships among players. I then identify underlying conditions and events at that particular moment and place that could have upset the continuity of daily practice. The resulting history emphasizes conflicts within the movement over the ethical arguments for and against industry relationships, shows points of stabilization, and makes visible the rules governing accepted practices.<sup>60</sup>

To capture the internal workings of the movement, I conducted interviews with forty women who had been decision makers at different points in time, and examined documents from the health advocacy organizations to which they belonged. I also drew from my own experiences as a former breast cancer patient who spent almost a decade in the breast cancer movement in the 1990s. I analyzed government reports, scientific literatures, industry documents, and media stories to situate these accounts of health activism in the scientific and policy contexts to which they belonged.

In addition to my interviews with health activists, I interviewed two key informants from the pharmaceutical industry, two from government policy circles, and one prominent cancer research scientist. Given the

polarization within the community on this topic and to encourage a frank discussion of their views, I offered participants the option of speaking under a pseudonym. Some chose to do so, and these names are referenced in the text and shown in the Appendix in quotation marks.

### **How the Book Is Organized**

The book has two main sections. Part 1 provides the policy background that informs the empirical investigation of the breast cancer movement in Part 2. The latter describes the growth of the movement over two decades, with a focus on relationships with the pharmaceutical industry. I conclude by examining the relationship between the movement and the industry and assessing what it means for health policy affecting breast cancer patients.

Part 1, comprising Chapters 1 and 2, relates the book's backstory: the dramatic reorientation in political philosophy that characterized Canada's transition from a postwar welfare state to a neoliberal state. From the early 1980s and into the 1990s, the country gradually aligned its policies with those of the Reagan and Thatcher governments in the United States and the United Kingdom respectively. The breast cancer movement, which had its origins in the late 1980s, is thus almost entirely a creature of the neoliberal period. Keeping in mind the unevenness with which neoliberalization proceeds, however, some structures and policies from the welfare state era remained in place into the early 1990s, and helped shape the early movement, as did activist resistance to the neoliberal project.

Chapter 1 outlines the central features of Canada's health system as it evolved, from the 1950s through the 1980s. The chapter provides essential background to Canada's publicly funded health care system – its significance and limitations, and some of the controversies it provoked. The contested nature of policy making is clearly seen, with its cast of characters working to push decisions one way or another, in a process that is seldom completely visible to the public. The transition to neoliberalism also saw dramatic changes in Canadian policies governing advocacy groups. Chapter 2 examines the pro-advocacy regulatory regime that governments developed in Canada's welfare state era and the resulting environment that enabled progressive social movements to flourish.<sup>61</sup> The latter

part of the chapter considers conditions that began to reshape the funding of nonprofits.

Part 2 tells the story of the breast cancer movement's beginnings and growth, with a focus on the gradual development of relationships between the grassroots groups and the pharmaceutical industry. Chapter 3 documents an initial grassroots period, in which small local groups of women diagnosed with breast cancer began to voice dissatisfaction with aspects of their experience as patients. The pharmaceutical industry had little role in these early groups, and drugs were a relatively minor topic of discussion, until a series of changes converged to bring the groups into sporadic contact with the industry, stimulating internal discussions about whether drug companies were an acceptable source of funding. Chapters 4 and 5 describe a period of contestation in which groups struggled internally with the ethics of pharma funding. Chapter 4 looks at external forces that challenged the feminist opposition to pharma funding. Chapter 5 provides case examples of internal tensions as debates within the groups redefined movement contours. By the third and last phase of my analysis (Chapters 6 and 7), most breast cancer groups had opted to accept pharma funding, normalizing the PHANGO construct. Chapter 6 describes a change in the sociopolitical landscape supportive of these developments and documents a process that systematized relationships between the industry and movement activists in response to critical attacks on the partnership model. In Chapter 7, examples of pharma-funded advocacy campaigns identify steps in these advocacy "dances" and illustrate their potential to affect pharmaceutical policies.

In the Conclusion, I reflect on what my findings say about how PHANGOs are constructed and maintained, and on the meaning of these partnerships for democratic debate, health policy, and patient groups as sites of knowledge that can advance patients' interests.