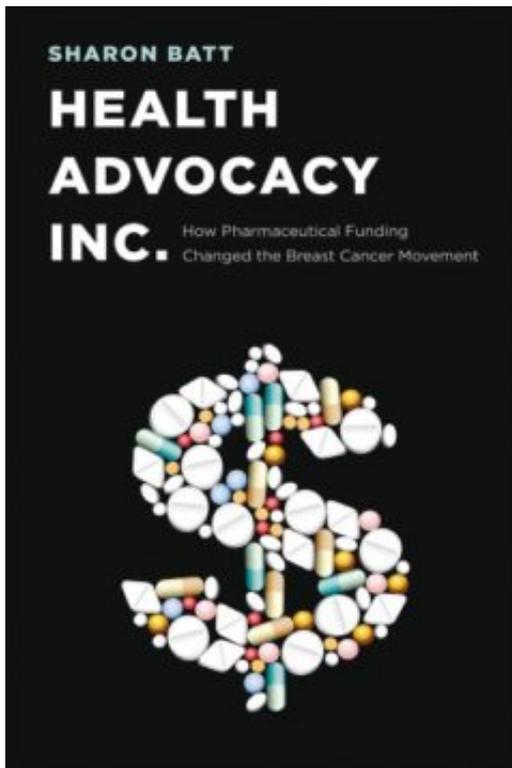


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Sharon Batt's Health Advocacy Inc. How Pharmaceutical Funding Changed the Breast Cancer Movement

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By Grazia De Michele



[Health Advocacy Inc. How Pharmaceutical Funding Changed the Breast Cancer Movement](#)

[Sharon Batt](#)

UBC Press, 2017, 383 pages

After being diagnosed with breast cancer in 1988, Sharon Batt became of the one the most prominent figures of the grassroots breast cancer movement that flourished in North America during the 1990s. A committed journalist and editor working mainly for feminist and consumer protection magazines, Batt was puzzled by the invisibility of breast cancer especially at a time when health activism was coming centre stage owing to the effervescence of the AIDS movement. She then co-founded the first breast

cancer advocacy group in Canada and wrote *Patient No More: The Politics of Breast Cancer* (Batt, 1994) considered, since its publication in 1994, a must read for all those interested in putting breast cancer activism into context. That book ended on a note of optimism: breast cancer activists had a rather bumpy road ahead, but their participation in the forging of a new breast cancer order, one in which old dogmas were eventually being challenged, held the promise of a better future.

More than twenty years later the movement has grown and changed. One of the main changes has been the gradual co-optation of a substantial part of it by the pharmaceutical industry. The phenomenon is analysed in Batt's compelling and thought-provoking new book, *Health Advocacy Inc. How Pharmaceutical Funding Changed the Breast Cancer Movement* presenting to the public the results of the work she carried out as a fellow in the Canadian Institutes of Health Research Training Program in Ethics of Health Research and Policy, sponsored by the Department of Bioethics at Dalhousie University and the W. Maurice Young Centre for Applied Ethics at the University of British Columbia.

As stated in the *Introduction*, one of the aims of *Health Advocacy Inc.* is to "reconstitute the process of division" that took place within the Canadian grassroots breast cancer movement among those accepting funding from the pharmaceutical industry and those refusing to do so (p. 3). The issue of patient groups taking "pharma" money is not peculiar to Canada or to breast cancer and has been already documented. However, according to Batt, the development of conflicts internal to groups and often leading to permanent ruptures has not been given due attention. Far from being "tedious exercises in ideological hairsplitting", as they are commonly seen, these conflicts are telling of the ways in which "social groups create and defend competing knowledge systems" (p. 4). As far as patients' groups are concerned, the struggles revolve around "what meaning we assign to drugs and drug companies, and the health and regulatory systems that control access to therapeutic technologies" (ibid). The role of economic, social and political forces is crucial in such meaning making process. The rise of neoliberalism produced a situation whereby public resources for the not-for-profit sector, including breast cancer groups, were gradually drained. In addition, the alliance between the state and industry, typical of neoliberal governance, altered the regulatory systems put in place to protect citizens from being harmed by drugs.

Batt proposes a periodization of the split within the Canadian breast cancer movement. During the first five years of its existence, from 1991 to 1995, participants in the movement engaged in debates over pharma funding occasionally, if a particular situation prompted them to arise. As the movement expanded rapidly in the early 1990s, generating enthusiasm among the public, the threat of cuts to governmental funding

and restrictions on charitable status for not-for-profit organizations loomed over the newly formed breast cancer groups. At the same time, the offloading to charities of services that the government was no longer providing, state overtures to the pharmaceutical industry, and healthcare cuts constituted further cause for concern. At this stage, however, “the groups had not clearly incorporated neoliberal discourse into their culture of action” (p. 120). Although arguments in favour of pharma funding were already being formulated, they were “still sketchy and ethically weak” (p. 121).

Between 1996 and 2001, the split into two rival camps became more evident. Batt refers to this as the “contestation period” (p. 123). Taking as a model Tony Blair’s social investment state, the Canadian Liberal government tried to restore the relationship with the not-for-profit sector, damaged by the early 1990s cuts, by favouring “organizations that posed no challenge to the state” (p. 125). Activist groups saw their already meagre resources further reduced. Competition among patient organizations was fierce, but so it was among drug companies owing to generics and products’ similarity. Rising overhead costs and declining profits made the situation even more stressful. Faster drug approvals became “the gold ring for the industry” (p. 142). Patient groups could hence serve as powerful pressure groups for this and other goals, including influencing governments, products’ promotion, access to data, clinical trials recruitment and many more. It was during the contestation period that groups began to debate and adopt formal policies reflecting “different understandings of the risks and benefits of cancer medications, of patients’ rights regarding medications, and of advocacy” (p. 183). For the supporters of pharma funding the target of advocacy shifted from the industry to government agencies, blamed for denying patients fast access to new drugs. Some of the organizations refusing to accept pharma funding had to shut their doors. Others, such as Breast Cancer Action Montreal, reinforced their own identity and, although they found themselves distanced from the rest of the community, had the opportunity to strengthen their links with the women’s health movement, whose main goals were still prevention and drug safety.

During the “partnership period”, spanning from 2002 to 2011, “pharma funding became the norm among Canadian breast cancer organizations engaged in advocacy, with only a small number of groups resisting the practice wholly or in part” (p. 187). The industry also took the partnerships as the new normal, concentrating on how to best implement them. The office set up by the Canadian federal government to facilitate public involvement in drug evaluation and approval recruited many people from pharma-funded organizations, thereby contributing to their normalization. In this phase the rift within the Canadian breast cancer movement often assumed bitter tones with members of pharma-funded groups protesting

that the conflict of interest lay in government funding of advocacy groups, whereas unrestricted educational grants could make receiving money from the industry ethical.

The last chapter presents three case studies concerning the role played by pharma-funded groups in constructing what Batt, following anthropologist Emily Martin, refers to as the “complex personalities” of drugs [p. 217]. The latter are not “just chemical or biological entit[ies]” [ibid], but they are endowed with social identities, shaped by a plurality of actors such as researchers, clinicians, drug companies and patients to name a few. A forth case study focuses on how groups’ claims that patients have the right to access new treatment drugs and have it covered by the state, regardless of their cost, are influenced by pharma sponsorships.

Health Advocacy Inc. is an extremely stimulating and timely book benefitting from the author’s scholarly skills, but also from her particular standpoint as a breast cancer activist. Academics, medical professionals and activists will find it useful to understand issues at the core of the current crisis of a medicine that nowadays seems to serve best the interest of the market rather than those of the patients. It is of utmost importance for the organizations that have taken on the responsibility of representing their interests to “take stock of where their power lies” – most notably in patients’ trust and in the support of the public – and use it to challenge the current system [p. 283].

[Grazia De Michele](#) is a doctoral researcher in history at the University of Genoa working on the history of the U.S. grassroots organization Breast Cancer Action since inception, in 1990, to 2010. She is also a breast cancer activist and editor of the collective blog [Le Amazzoni Furiose](#) (The Furious Amazons) that she founded in 2012.

Reference

Batt, S. (1994) *Patient No More. The Politics of Breast Cancer*, Gynergy Books

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