The larger nonprofit foundations threw in at least $100 million more, not to mention the myriad smaller fundraisers in many communities. And no one really knows how much industry invested. Multiply that by, say, 20 years, and you come up with a staggering number.

As patients, we give parts of our bodies to science. We lobby for research funding. We write checks and pay taxes to support it. We give those funds and those biological resources—us—to institutions and scientists, to search for drugs and other interventions to save lives.

Breast cancer research is big business. And the incentives in that business are designed to benefit industry, doctors and institutions, leaving patients behind. In 2018 alone, about $1 billion federal dollars were invested in institutions around the country to fund research.

Conflicts have killed trust in the system. Advocates must rebuild it

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Patients and advocates cannot afford to be silent bystanders in all of this. A key result of this focus on financial gain is that we, as patients and the public, have lost trust in this system. And that trust will not be regained by tweaking the process, issuing new disclosure rules or calling for one-sided partnerships with patients. We are not asking for a cut of the millions. We are asking for a system that truly has the goal of saving our lives at its core.

The existing system and the relationship among researchers, doctors and other industry stakeholders demand that the system be thoroughly investigated and revamped and that advocates be at the forefront.

Why advocates?
We have no agenda other than to end breast cancer. As a patient advocacy movement, we are not here for personal financial gain or publication or patent rights or tenure or status among our peers. We feel the urgency, we live it.

The basis on which the research and health care enterprise in breast cancer is built, is you, me, all of us who have had breast cancer, the millions who will develop it, the many more millions who have been touched by it, and all of us who support its end.

In breast cancer, these drugs rarely extend life and usually cost so much that they often bankrupt patients and the health care system.
We are more than capable. NBCC educates advocates to understand the process, language and concepts of breast cancer science and research and the health care system.

We give advocates the tools to become leaders in these arenas and contribute meaningfully to decision making. Trained, educated advocates should be setting the research agenda, collaborating on research generation and conduct and helping set rules to foster transparency and minimize conflicts of interest and they should oversee their implementation.

We cannot afford to just keep playing along.

Of course, many in the scientific community discuss system change using terms such as “patient centered” and “patient engagement.” They call for patient partnerships, but it seems clear that they mean something very different about our role, than we do.

Their idea of participation is to ask patients to contribute to their research with funding and their bodies, or as tokens to check a box in the conduct of their work. They want our tissue, our blood, our medical information.

We completely understand that our records and tumor samples and other biological resources are vitally important to scientific research. Not to mention the funding we give and raise and lobby for. But we should not be asked to simply be donors. We cannot just turn over those funds and our bodies to this existing system.

Trained and educated advocates with a constituency should have a significant leadership role in determining what they do with our bodies and with those funds.

In setting the research agenda and systems of care. In implementing true transparency throughout both systems. In redesigning the system at all levels.

And not advocates whose support can be bought with a check or a token seat at the table. Real, trained advocates with a constituency, who can speak for others and have the courage to do so. Because right now the system we live in—and die in—is one that focuses on financial gain, where conflicts abound and the doctors that care for us, the scientists that pursue breast cancer and the institutions that proudly operate under the guise of a “nonprofit” too often are motivated by financial gain.

“It is clear that the many millions of dollars that flow among those players skew the process and lead us to question if the real goal is to save lives or sell patent rights.”