



WEB EXCLUSIVES

Advocates Put Triple Negative Breast Cancer to the Test

BY KATHY LATOUR

Allison Axenrod and Hayley Dinerman first met Nancy Block-Zenna in 2003 at a "Mommy and Me" class in Bergen County, New Jersey. The new mothers, all professional women who had taken time off to do the mommy track, became instant friends. They met weekly for a playgroup and soon were part of each other's larger communities.

So, when Block-Zenna was diagnosed with breast cancer in 2005, her community jumped in to help. Robyn Littman, a friend of Nancy's since childhood, raised money for Nancy's treatment, which they feared wouldn't be covered by her insurance. Littman and her husband, who own a printing company, raised more than \$9,000 selling beach towels and T-shirts with their "Peace, Love and a Cure" campaign, which featured a peace sign, a heart, and a pink ribbon.

Dinerman and other friends helped research the disease, only to learn that Nancy's treatment options were limited. Because her type of cancer was triple-negative, meaning her cancer was not fueled by estrogen, progesterone, or HER2 (human epidermal growth factor receptor 2), it meant that newer, targeted agents would have no effect, and her only option was chemotherapy.

"We scoured the Internet, but found very little substantive information about triple-negative breast cancer," says Dinerman. "The two articles we did find focused on the prevalence of the disease in African-American women, but said virtually nothing about the disease itself, the current state of research, or any significant research studies."

A Foundation is Born

When Block-Zenna learned her treatment would be covered under her insurance, her friends, literally sitting together at the weekly playgroup, decided to use the \$9,000 to start the Triple Negative Breast Cancer Foundation -- with a mission to raise awareness of the disease and to support scientists and researchers in their efforts to determine the definitive causes of triple-negative breast cancer, so that effective detection, diagnosis, prevention, and treatment can be pursued and achieved.

What happened next can only be called an explosion of passion. Axenrod, the

volunteer executive director, was researching doctors who might know something about triple negative when she came across Eric Winer, MD, director of the Breast Oncology Center at Dana-Farber Cancer Institute in Boston. Winer is also the Chief Scientific Advisor for Susan G. Komen for the Cure. Axenrod e-mailed him a note about their plans for the foundation.

“He didn’t know us at all, but he e-mailed me and said let’s talk. He was in London at the airport waiting for a plane, and we talked for an hour,” Axenrod recalls. “He said this needs to be done, someone should have done it before.” He also offered to help in any way he could. He suggested the group call Lisa Carey, MD, at the University of North Carolina School of Medicine and medical director of the UNC Breast Center. Dinerman, chair of the all-volunteer board and staff, picked up the phone and dialed the number, expecting to leave a message. Carey answered, offering the same excitement shown by Winer.

Both Axenrod and Dinerman still marvel that “in their ignorance” they were able to contact these two leading physician-researchers who offered their assistance in any way they could.

Gaining a Presence

Another board member helped create the group’s website www.tnbcfoundation.org, which has surprised the board by becoming the primary forum for women with triple-negative breast cancer.

“We put the website up to raise money, but there was an amazing response we got from the women in the community who needed this,” Dinerman says.

Axenrod says the foundation will be upgrading the site this year to help deal with traffic. “They rely on this as a lifeline. We want to give them what they need.”

The Foundation’s first fundraiser also grew from a playgroup relationship.

“Another one of the founders of the Foundation, Sharon Fredman, was in a baby playgroup with Malaak Compton-Rock, the wife of comedian Chris Rock,” says Dinerman. “She told Malaak about Nancy and plans to raise funds for triple-negative research.”

Compton-Rock, who has long been involved in philanthropy, offered her home for the inaugural fundraiser in June 2007 to launch the Foundation. Some 240 people attended and the group raised \$230,000.

Block-Zenna spoke to the group that evening. Both Dinerman and Axenrod recall the power of her words.

“She encouraged people to support the Foundation so no other mother would have to go through this, and no other daughter would have to lose her mother,” Axenrod says.

Dinerman recalls her looking around the room, knowing how many there had daughters the same age as her daughter Jolie.

“She wanted people to know that if we continue this fight, by the time our

daughters come of age it won't be the threat it is today," Dinerman recalls.

Nancy Block-Zenna died two months later. Her group of friends, Axenrod says, threw themselves into the foundation to deal with the grief.

Axenrod says that Winer had asked if the group would still raise funds if Nancy died.

"He said, 'I want you to know that you are too late to help Nancy, so you have to go into this knowing you can't save her. Do you still want to do this? Even after she is gone, you will still want to do this?'" Axenrod said.

"But it wasn't until she died that we knew how much more committed we were because we lived it with her. To sit by hopelessly and watch what happened to her. Because we already had the foundation started, we could throw our grief into the foundation."

The San Antonio Breast Cancer Symposium

This past December, four months after Nancy's death, the Triple Negative Breast Cancer Foundation sponsored the first ever symposium dedicated to triple-negative breast cancer in conjunction with the San Antonio Breast Cancer Symposium. Dinerman, the Foundation chair, described the event as a "think tank" aimed at establishing the state of triple-negative research and determining the most promising avenues for future research.

This year the foundation held its second meeting on the day before the official symposium began, and a white paper based on 2007's discussions is being published in an upcoming CCR Focus.

What the Future Holds

The Triple Negative Breast Cancer Foundation has also announced The Susan G. Komen for the Cure Promise Grant, co-funded by the Triple Negative Breast Cancer Foundation.

"We have similar motivation," says Diana Rowden, Vice President for Health Sciences for Susan G. Komen for the Cure. "Komen and the Triple Negative Breast Cancer Foundation both recognize the need for research into triple negative breast cancer, so it's the perfect collaboration."

"Dinerman says the foundation board wanted to be very careful in donating funds because they were looking for just the right project. Now that we are teaming up with Komen, and we see the selection process for the promise grant, we know that they really are ensuring that projects with real world impact will rise to the top."

The Triple Negative Breast Cancer Foundation gave 80 percent of the funds raised to date to provide initial funding to the \$7.5 million dollar grant with additional donations expected.

“We have had so many organizations approach us about funding, but because none of us have a medical background, we didn’t feel confident to assess the projects. We know that Komen has that expertise.”

Komen has received 18 triple-negative breast cancer proposals, and Dinerman says they expect the best research proposals to rise to the top and be funded.

Today Block-Zenna remains an active presence in the foundation through her daughter Jolie, now 6.

“She goes to school with my twin daughters,” says Dinerman. “She is always here to remind us.”

Read more of *CURE's* coverage of the 31st annual San Antonio Breast Cancer Symposium at <http://media.curetoday.com/htmlmail/sabcs>.