

Women selflessly donate breast tissue to unique bank: The story of the Komen Tissue Bank at IU Simon Cancer Center

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Theresa Mathieson, calls it a lab in a box.

Everything she and a team of volunteers will need to process samples from more than 150 women who are donating healthy breast tissue is in the so-called lab in a box. Mathieson, (now the former) biospecimen manager at the Susan G. Komen Tissue Bank at IU Simon Cancer Center, actually has many boxes. The boxes contain everything needed to create a lab for human sample handling from lab coats, eyewear, and gloves for lab volunteers to centrifuges, pipets, test tubes, cryovials, and tissue cassettes. The boxes have been moved to the Hematology Clinic and Women's Center on the second floor of the Indiana University Melvin and Bren Simon Cancer Center in preparation for the collection event about to take place.

Mathieson and her crew have only a few hours to unload the boxes and get everything up and running before the first women begin to arrive for their appointments. One exam room is transformed into a lab in which tissue will be both snap frozen and formalin fixed, while another exam room is made into a lab that will process whole blood into serum and plasma.

Slowly, more people -- all volunteers sporting bright green T-shirts -- begin to arrive on the second floor. Each has a role for the day, ranging from consenting donors and helping women fill out a medical questionnaire at a bank of computers to phlebotomists, surgeons and surgeon assistants, donor escorts, room coordinators, and sample runners that quickly carry the samples from the collection location to the labs.

By 8:00 a.m., it's show time. The first women, who have left their homes with a determination to help breast cancer researchers, have arrived for their appointments. Some are no doubt nervous and anxious because they are unsure of what to expect, and they're wondering if it will be painful. After all, during the procedure, a tissue sample is taken from one breast with a needle after local anesthesia is administered. The amount of tissue taken is about one gram (or the size of two peas). However, their determination wins out because they know that other women -- their mothers, daughters, sisters, aunts, friends, neighbors, and others -- have died from breast cancer or are fighting it. For them, it's an easy choice.

Once tissue has been removed from a woman, Theresa's team goes into action to process it within five minutes. "We try to keep the samples as close as possible, physiologically, to what they are in the body," Mathieson said. "We don't want the blood chemistry to have time to change. And we minimize the cellular and molecular alterations that tissue undergoes once it's removed from the body. The sample collection and processing procedures are standardized to minimize pre-analytical variability."

It's a well-orchestrated production that the staff and volunteers of the Komen Tissue Bank -- the world's first and only healthy breast tissue bank -- have been doing since 2007. By collecting samples from women without breast cancer, researchers will be able to determine the differences between healthy and cancerous tissues, which could lead to a better understanding of the disease. In all, more than 1,850 women had donated a precious piece of themselves by the end of 2011. (At the time of revision, over 4,600 women have donated tissue.)

Nearly 700 women -- more than one-third of the number of women who had already donated in the past -- donated breast tissue during Indy's Super Cure, a bold initiative developed by the 2012 Indianapolis Super Bowl Host Committee. On Jan. 28 and 29, 2012, the weekend prior to the Super Bowl, Indy's Super Cure took place at the IU Simon Cancer Center. Six hundred volunteers, more than seven times the number needed during a typical collection, donated their time to help run Indy's Super Cure. Because Indianapolis was on the world stage when it hosted Super Bowl XLVI, the host committee's goal was to raise both awareness and funds for the tissue bank since it announced Indy's Super Cure in July 2011. "We want to take that international spotlight (of the Super Bowl) and shine it on this great community asset for the world to see," Allison Melangton, president and chief executive officer of the host committee, explained.

For the tissue bank's co-directors, Anna Maria Storniolo, M.D. (now executive director), and Susan Clare, M.D., Ph.D. (no longer with the tissue bank), they could never have imagined such a boost. Nor could Connie Rufenbarger, a two-time breast cancer survivor from Warsaw, IN. First diagnosed in 1982 at age 34, Rufenbarger vividly remembers when there were no pink ribbons, no walks, no races for breast cancer awareness. There was also no readily helpful information -- whether in brochures or pamphlets -- for newly diagnosed women like there is today. "I had to do something," Rufenbarger, a former school teacher, said.

She became an advocate and project director of the Catherine Peachey Fund, a nonprofit dedicated to supporting cutting-edge breast cancer research named in honor of Rufenbarger's dear friend who died of breast cancer. Rufenbarger also took part in the National Cancer Institute's Breast Cancer Progress Review Group (BC-PRG), which in 1998, reported that progress in breast cancer research was hindered by not "understanding the biology and developmental genetics of the normal mammary gland." Rufenbarger assumed progress would be made obtaining normal controls since the country's leading scientists collectively knew what was needed.

Six years later at the 2004 annual meeting of the Amelia Project -- an annual scientific meeting administered by the Peachey Fund and funded by the Indianapolis affiliate of Susan G. Komen -- Indiana breast cancer scientists and clinicians once again bemoaned the lack of "normal" specimens. Rufenbarger, a woman who had been crusading since her own breast cancer diagnosis 22 years earlier, stood up at the meeting and said, "I can't do the science, but if you need women to give you tissue, done deal."

Rufenbarger next went to the late Stephen Williams, M.D., the IU Simon Cancer Center's founding director. "I told him what I wanted to do. He said, 'You don't know what you're getting into. But if you can make this happen, you have my permission to try, and I will try to help you,'" she recalled about the meeting.

Dr. Storniolo, a compassionate medical oncologist, was new to Indiana University when she was first approached by Rufenbarger. Rufenbarger told the doctor that she wanted to create a breast cancer prevention program at IU. Dr. Storniolo needed some time to think about it, and she told Rufenbarger about all of the roadblocks to expect. "All kidding aside, Connie truly is a force of nature," Dr. Storniolo said. "I have never met anyone like her. She is truly the most selfless person I have met." Dr. Storniolo said yes. When Rufenbarger saw a need to create a bio-repository of "normal" breast tissue, she again turned to Dr. Storniolo to take the lead.

A year later, Bryan Schneider, M.D., then a fellow in the Division of Hematology Oncology at IU School of Medicine, had designed a study in which he needed DNA from women without breast cancer. Rufenbarger learned of the young Schneider's need and suggested a blood collection at the 2005 Komen Indianapolis Race for the Cure. The result? They collected an amazing 1,200+ whole blood samples.

Equally impressive, the event -- dubbed Friends for Life -- proved that women would willingly give of themselves in the fight against breast cancer. In order to provide a permanent and secure repository for those samples, Mary Ellen's Tissue Bank, named in honor of Mary Ellen Allarding, was established.

Rufenbarger approached Dr. Clare and inquired if she would be willing to share an Oracle-based database she had helped create. The talented surgeon quickly shared it. "Sue's database was absolutely a gold mine for us," Rufenbarger said. All of the right ingredients had been falling into place at the right time for the world's first healthy breast tissue bank to become a reality.

Other collection events soon were scheduled in which saliva (no longer collected now) and serum were also obtained in addition to breast tissue and blood. The acquisition, processing, storage, retrieval, and dissemination of the specimens would be performed according to best practices established by the National Cancer Institute.

In the spring of 2007, Drs. Storniolo and Clare were attending the Translational Breast Cancer Research Consortium in Texas. Delayed by a snowstorm in Milwaukee, Dr. Clare arrived late at the meeting and took the last remaining seat. She happened to be seated next to a patient advocate, Cindy Geoghegan, who was also a contractor for Komen. Geoghegan wondered why the doctors had never contacted Komen before. Dr. Clare explained they had been unable to get a meeting with Komen. Geoghegan next asked Dr. Clare if she and Dr. Storniolo could remain in Texas for an extra day. So, Dr. Clare jotted down a note and passed it over to Dr. Storniolo, who responded that she could not. Dr. Clare re-sent the note, this time referencing the fact that it was for a meeting with Komen. Dr. Storniolo said yes, she'd be there. And Rufenbarger joined them.

The trio met with Hala Modellmog, then president and CEO of Komen. When asked where the tissue bank's funding comes from, Dr. Storniolo told Modellmog, "Well, it's month-to-month." Modellmog asked what it would take not to be month-to-month. "I think a million dollars a year would do it," Rufenbarger said. And so, amazingly, it happened. Komen gave \$1 million to start the Susan G. Komen Tissue Bank at the IU Simon Cancer Center, the world's first and only healthy breast tissue bank. The threesome remained calm, cool, and collected ... until they got inside of an elevator at the Komen

headquarters. That's when they cheered and celebrated their accomplishment, which was likely heard beyond the elevator which is located inside an open atrium.

Komen got the ball rolling, but in the last few years several more organizations, including The Breast Cancer Research Fund, Oracle, The Catherine Peachey Fund, Vera Bradley, Wheaton, and Hologic, as well as others through the Indy's Super Cure, have joined to help support the Tissue Bank through funding and in-kind donations.

"From the very start, this has been a great idea from an advocate – Connie Rufenbarger – and a lot of hard work from a whole lot of people," Dr. Storniolo said. "If we can understand what's going wrong, we can understand how to fix it."

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