

Indianapolis' Super Bowl provides a prime opportunity to raise awareness about the Komen Tissue Bank



SUPER Women SUPER Cure

by Laura Kruty

It started out as a typical girls' get-together. Allison Melangton, president of the 2012 Indianapolis Super Bowl Host Committee, invited a few girlfriends to her Carmel home one night in October 2010. With ESPN running NFL highlights in the background, the women started chatting about their lives, their kids — and cancer.

One of the women there, Traci Runge, was right in the thick of treatment for breast cancer, which was diagnosed in April 2010.

Melangton's attention turned to the TV.

"All the players were wearing pink," she recalls. "I was looking at it, thinking, *It's amazing how much the NFL has grown in their support of breast cancer awareness.* Even the referees' whistles were pink."

As the night wore on, they started journaling for Runge, jotting down her experiences in battling cancer.

And that's when the night became not simply a girls' night in, but the start of something much bigger. Melangton thought of the football highlights she had just watched. And she thought about what Runge was going through.

"Maybe it's because I'm a female leading a

Super Bowl Host Committee," Melangton says.

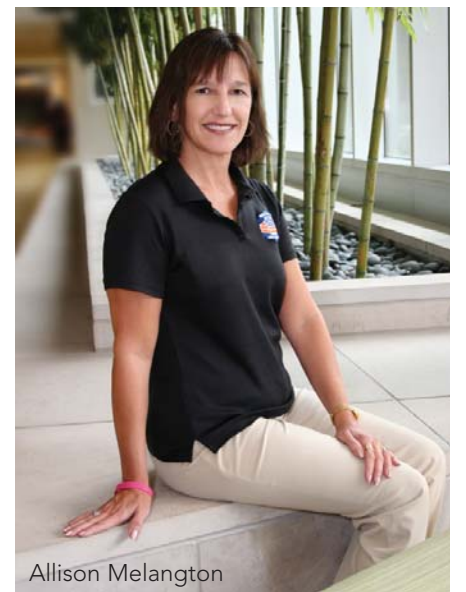
Her idea was to use Indianapolis' Super Bowl to raise awareness and money for the Susan G. Komen for the Cure Tissue Bank at the IU Simon Cancer Center.

Shortly after that night, Melangton met with Cathy Langham, vice chair of the Super Bowl committee and president of Langham Logistics. With their plates not just full but overflowing, the women were reluctant to take on another project.

"She said, 'We can't afford *not* to do it,'" Melangton recalls. "'We're going to regret not doing it.'"

Indy's Super Cure was officially off the ground. The initiative's goals are to use the visibility of the Super Bowl next February to increase the number of donations to the Komen Tissue Bank, raise money to financially support the bank and increase awareness both in central Indiana and around the country.

Indy's Super Cure boasts two invaluable supporters: Runge and Lisa Miller, both central Indiana residents and the only women to have donated both healthy and cancerous tis-



Allison Melangton

sue — potentially leading to groundbreaking achievements in breast cancer research.

A friendship blossoms

One night 13 years ago, Melangton's doorbell rang. She was tired and overwhelmed after watching over her son Cameron while he was in the hospital with an illness.

Traci Runge



“He just held me and we cried. I knew it was very aggressive. I knew it was my entire breast. You think, Am I going to die? I wanted to be there for my girls.”

There stood a girl — “the most adorable little girl I’ve ever seen,” Melangton says — with a large package and her mother standing behind her.

The girl, Hannah Runge, said, “I’m in Cameron’s class in school, and I heard he’s sick, and we wanted to bring some gifts to make him feel better,” Melangton recalls.

“I told her how much we appreciated it, and that was the start of a long friendship.”

Hannah and Cameron were best friends throughout school. And their moms forged a friendship of their own.

“In many ways, we are so alike, and, in many ways, we are so different,” Melangton says. “I think we have similar spirits.”

The battle begins

While coaching cheerleading, Runge, a Carmel resident, watched as one of her students’ mothers fought breast cancer.

“My heart went out to her,” she says. “We were both pregnant at the time. I thought, *How can I help save her?*”

In 2007, after reading a story in the newspaper about the Komen Tissue Bank, it occurred to Runge that donating tissue was the best way to help. Along with a friend, she underwent the procedure at Clarian North Medical Center.

But it nearly didn’t happen.

“They almost turned us away,” she says. “You had to preregister. I said, ‘Can’t you take just two more?’”

Three years later, Runge’s first thought after feeling a lump in her breast was that it was an injury from training for her first triathlon.

But a couple weeks later, Runge’s husband Dan noticed that the lump had grown. A mammogram and ultrasound showed cancer was present, but she had to wait for the biopsy results.

“That week of the unknown was awful,” Runge says. “You don’t say a thing to anyone because you don’t have answers.”

On April 15, 2010, after the couple’s three daughters (then 6, 12 and 16) were in bed, Runge received the news she was hoping and praying she wouldn’t.

“Dan just held me and we cried. I knew it was very aggressive. I knew it was my entire breast. You think, *Am I going to die?* I wanted to be there for my girls,” she says.

Runge, who volunteered at her daughter’s schools in the Carmel Clay district, started eight rounds of chemotherapy and had a mastectomy the day after her 42nd birthday.

“What a birthday gift,” she quips with a laugh. She had no family history of breast cancer.

Later that day, Runge and a friend headed downtown to pick up their Susan G. Komen for the Cure race packets. While there, it dawned on Runge to again donate tissue to the bank. It was the epiphany she had been looking for.

“That week of the unknown, I just prayed and said, ‘Lord, show me my purpose,’” Runge recalls.

Runge quietly walked the route the next day, the words “One-Day Fighter” on the back of her shirt. Surrounded by pink as far as the eye

could see, it was the best possible situation for Runge.

“I think I needed to be there. I knew then I was going to have a positive attitude toward it and be there for others.”

Throughout Runge’s bout with cancer, Melangton was right there lending a hand.

“She took me to chemo, cleaned my house and made meals,” Runge says. “While I was sick, she was working to figure out how to bring awareness to the tissue bank.”

A self-described “fixer,” Melangton also urged Runge to accept help from those that were offering. “She always reaches out and does everything for everybody else,” Melangton says. “I encouraged her to be open and honest with what her family needed while she was having treatment.”

Doing her part

Unlike Runge, Lisa Miller has an extensive family history of cancer. Her mom is a breast cancer survivor. Her aunt lost her battle with ovarian cancer. Her cousin had breast cancer, which has come back after 17 years. And that woman’s daughter, who is 36, is battling cancer as well.

All of that is why she decided to be tested for the BRCA-1 gene in 2008. She learned she did carry the gene, and, at that point, opted to have a complete abdominal hysterectomy.

As an administrative assistant to breast oncologists for many years, Miller was familiar with BRCA-1 and bilateral mastectomies.

Earlier this year, though, those terms took on a much more personal meaning.

In January of this year, Miller decided to have a prophylactic mastectomy to reduce her risk of breast cancer.

On Feb. 27, despite the precautions, Miller learned she had triple negative breast cancer, a highly aggressive form of the disease. She began chemotherapy on March 17 and recently had a bilateral mastectomy.

“Having worked in and around breast cancer and patients and breast oncologists for the past 15-plus years, I knew what this diagnosis meant,” Miller says. “It was not only a physical fear I felt, but I immediately thought of my two daughters (23 and 26) and what this is going to mean for them.”

“Knowing I was already a BRCA-1 carrier, I didn’t want them to go down this route ever.”

Through her job, Miller learned about the Komen Tissue Bank when it was still in its infancy.

“When you’re in and around that environment, you hear about studies going on and you think, *Could I be a part of that study?*”

Miller had blood drawn on the day the bank debuted at a Susan G. Komen for the Cure event downtown. In January 2008, she donated breast tissue.

“It was one of those things where you’re in and around it, and everyone else is doing it, so you going to go ahead and do it,” she says. “I really wasn’t motivated by one particular story; I just knew I wanted to do it.”

Miller’s doctor, Anna Maria Storniolo, professor of clinical medicine in the hematology/oncology division at the IU School of Medicine, encouraged her to donate tissue after Miller was diagnosed.

“I thought, *Absolutely,*” Miller says. “I want to beat this disease

Lisa Miller



“It was not only a physical fear I felt, but I immediately thought of my two daughters and what this is going to mean for them.”

as hard as we can. It was a club I never anticipated being a part of and never wanted to be.”

Miller, whose husband Mark has known Melangton as a business associate for quite some time, says it was a no-brainer to donate tissue, especially after seeing the enthusiasm of the oncologists she worked so closely with for more than 15 years.

Now she's an advocate for genetic counseling to fully understand the BRCA-1 gene, something both of her daughters carry.

“The information you gain from understanding this diagnosis of being a carrier is just incredible,” Miller says. “If somebody does crop up positive, everyone should have an excellent understanding of it.”

Despite each being dealt a hand of cancer, Runge and Miller look at their diagnoses as blessings in disguise — especially given the possibilities that could stem from their tissue donations.

“You're like, *Wow*,” Runge says. “What if they could find a cure? Do you know how many women's lives that one donation could save?”

“At the time, I was doing it, because if I was going to die, I was going to do everything I could to save my daughters. Now the possibility of not only saving my daughters but so many other people — that's the biggest blessing I've been given.”

Miller says most people ask her how she can look at cancer as a blessing.



Photo by Molly Connor/Meg Miller
Lisa Miller, flanked by daughters Andrea and Meg Miller

“You have to look at whatever comes your way as positive somehow,” she says. “This journey, as awful as it's been, has been positive.”

Miller says she's in awe of Runge.

“We're definitely in this together,” Miller says. “A close relationship has already begun. She's an amazing lady.”

Indy's Super Cure

The Super Bowl is expected to attract nearly 150,000 visitors to Indianapolis, the vast majority coming from out of state. That's a lot of people to educate about the Komen Tissue Bank. But the goals of raising awareness and garnering more tissue donations aren't solely aimed at out-of-state visitors.

“The tissue bank has had 1,500 tissue donors so far,” Melangton says. “The majority of that database is Caucasian. Our first goal is to help diversify the donors. I think we're making great strides with that.”

Another goal is to raise money to financially support the bank, a large portion of which will come via a fundraiser on Nov. 19. And a third goal is to educate the public and researchers about the tissue bank and research advances that can come from it.

To these ends, tissue donations are scheduled for Jan. 28-29. The National Football League and the host committee are promoting Indy's Super Cure on their websites, and researchers involved with the Komen Tissue Bank are out speaking to the public about it.

“We have a perfect storm here, being the location of the bank, having the first two residents that are matches and then the Super Bowl,” Melangton says.

Runge says Melangton has done so much to raise awareness not just in central Indiana but all over the country.

“It couldn't have been done without Allison's help,” Runge says. “I don't know how it could have come to what it is today.”

“I don't feel any of this was an accident. I don't think it's ironic that we have the only tissue bank in the world, and she's the female Super Bowl president. I think this was God's plan. All the pieces fit perfectly.”

Melangton calls the tissue bank and its founders “amazing gems and assets in the community.”

“They are remarkable women doing remarkable things,” she says. “They're solving breast cancer. There's not a lot of people who can say that.”

“They're making traction. And it's right here.”

The *Only* One of its Kind

A closer look at the Komen Tissue Bank

Dr. Anna Maria Storniolo



Photo by Dan Kraker

In 1998, the National Cancer Institute commissioned the Breast Cancer Progress Review Group to create a report looking back on 10 years of treating and diagnosing breast cancer, as well as looking forward 10 years to identify goals.

One goal was to understand the development of the normal breast in order to identify the origins of breast cancer, says Dr. Anna Maria Storniolo, director of the Catherine Peachey Breast Cancer Prevention Program and professor of clinical medicine in the hematology/oncology division at the IU School of Medicine.

Six years later, during a talk at a conference in Indianapolis, the importance of understanding the normal breast was again a hot topic. A young investigator reported that a lack of normal controls was a serious hurdle to the success of her research.

Audience members didn't understand why a database of normal blood and tissue specimens wasn't available. The keynote speaker, an NCI official, said that, even if there were a way to donate, women simply would not voluntarily donate breast tissue.

One woman in the audience, Connie Rufenbarger, refused to accept that.

“Connie piped up and said, ‘Have you ever asked women?’” Storniolo recalls. “The answer was, ‘There's no way.’”

“Connie was not going to let go of this idea.”

In 2005, Bryan Schneider, assistant professor of medicine at the IU Simon Cancer Center, needed blood specimens from hundreds of women — both with and without breast cancer — for a study he designed.

Rufenbarger learned of this need and suggested collecting blood samples at that year's Susan G. Komen for the Cure event.

And so it happened. With the help of more than 200 volunteers and phlebotomists, 750 samples were procured in three and a half hours. “Otherwise, it would have taken two to three years,” Storniolo says.

It became clear to researchers that women absolutely were willing to donate blood in the name of helping other women. With two additional blood collections under their belts, they started collecting breast tissue samples, slowly at first, with four samples before increasing that number to 30.

“We showed that all you had to do was ask — at least in the good-hearted state of Indiana,” Storniolo says.

Eventually, a waitlist of women wanting to donate was established. In 2007, Susan G. Komen for the Cure awarded a \$1 million grant, and the Susan G. Komen for the Cure Tissue Bank at the IU Simon Cancer Center was officially established.

Storniolo is co-principal investigator along with Dr. Susan Clare, an assistant professor in the department of surgery at the IU School of Medicine.

How it works

Tissue collections take place about five times a year. Women complete an electronic questionnaire about their medical and family health history.

“These specimens aren't just random samples,” Storniolo says. “We're able to know quite a bit about the lady from whom that specimen came.”

Collecting a blood and tissue sample takes about one hour. As Melangton, Runge and Miller can attest, it's a quick and relatively painless procedure.

Each donation consists of two to four tissue slivers and a blood sample. Those can be split up into various slides, so that each donation has the potential to be involved in 25 to 30 experiments, Storniolo says.

“Everything is collected by strict procedures,” she says. “The blood has to be spun within a certain number of minutes. The tissue samples have to be in liquid nitrogen within five minutes.”

Many samples also include a digital copy of the woman's mammogram.

Researchers from around the world can request access to the specimens, provided they have proof of funding. Three independent reviewers ensure the proposed research would be a good use of the specimens.

Once the proposal is approved, the samples are sent to the researcher with the agreement that the data they find be sent back to the tissue bank to be made available to other investigators.

This is in an effort to accelerate research and the timeline for both prevention and a cure, Storniolo says.



Breast tissue cores recently removed from a donor

Furthering research

Several researchers are using tissue samples to examine the development of the normal breast.

“I don't think there's another organ in our body that goes through more changes in a natural lifetime,” Storniolo says. “It's a very complicated organ, and to understand what leads to cancer, you need to understand the processes and how they're supposed to happen.”

One researcher is looking at gene analyses from women in two phases of the menstrual cycle, and another researcher is examining samples from women who have triple negative breast cancer and those that do not have cancer.

Storniolo says the Komen Tissue Bank is a model for other cancers and diseases.

“It's also a model for getting the lay public involved and invested in research,” she says. “Until now, the only way you could participate in research was to have the disease.”

Storniolo recalls the story of a woman who came to the bank in a wheelchair with clearance from her cardiologist to donate. She had with her five daughters and one granddaughter, all of whom were from out of state.

No one in the family had cancer. But it was something the 86-year-old grandmother felt strongly about participating in.

“Unless women step up to the plate and help find out what's going on, we're never going to beat this,” Storniolo recalls her saying.

“(Women are) coming of their own will and saying, ‘Take a piece of my breast.’ It just boggles the mind. We have a waitlist that will not end.”

Storniolo says the tissue bank, a true grassroots effort, owes its success to its location.

“It's been said, half in jest, that this could only have happened in the Midwest. This is Hoosier pride and Hoosier spirit at its best. This is just amazing, amazing proof of how magnanimous people around us are.

“It's the most humbling thing I could ever do. People say to me, ‘Next to my wedding and the birth of my children, this is the most exciting day of my life.’” **W**