

THE JOHNS HOPKINS KIMMEL CANCER CENTER

# BREAST MATTERS

2020/2021



[Inside]  
**A BETTER WAY**

Harnessing the Power of Breast Cancer Prevention

**WOMEN'S WELLNESS**

**ANGELA'S STORY**

**AND MUCH MORE**



When Leslie Ries's grandmother was diagnosed with breast cancer in the early 1940s, there was no understanding of BRCA mutations or the grip the disease would have on future generations of the family.

## A BETTER WAY

Harnessing the Power of Breast Cancer Prevention

Her diagnosis came decades before drug and radiation therapies for breast cancer. The cutting edge science at the time was very literally focused on the cutting edge of the scalpel with surgery—in the form of Halsted's radical mastectomy—that removed the breast, muscles and lymph nodes under the arm. Later on, parts of her brain were removed after the cancer spread there by metastasis.

Leslie imagines how it must have been for her grandmother, when more and more of her body was carved into and cut away as the disease spread, ultimately claiming her life. Although her grandmother died before Leslie's parents were even married, the source of this cancer was already eerily shaping Leslie's future and that of her daughters.

As far as we've come in understanding and treating breast cancer, the life-altering experiences of women and their families is a jolting reminder of how much farther we have to go and the dire need for prevention.

"I've seen the devastation too many times," says Leslie. "Mothers gone, leaving behind young children. We have to intervene to protect ourselves, our children and others from getting this disease. Breast cancer is a trauma to the whole family."

She understands that trauma all too well. Her own diagnosis came 15 years ago.

Leslie tested positive for a BRCA mutation, a genetic alteration that can occur to one or both types of breast cancer susceptibility genes (BRCA1 and BRCA2). It alters the body's ability to repair DNA, placing those affected at higher risk of developing breast cancer. This inherited alteration, potentially affecting multiple generations of families, is also associated with other cancers in men and women, including ovarian, prostate and pancreatic cancers. The mutation caused her cancer and now also threatens her two daughters.

Leslie is grateful to be a survivor and for the progress that has been made since her grandmother's diagnosis more than 70 years ago. After enduring a double mastectomy and reconstructive surgery, and 4 months of chemotherapy, she considers herself fortunate and grateful. She doesn't deny that treatment saves lives, but she also knows it's not enough.

"The improvements in treatment options and reconstruction are wonderful, but they still come at a great cost," she says. "The long-term emotional, physical and financial tolls are immense and often irreparable. We have to do better."

Leslie's own experience and that of so many other families made her realize, "We have to think differently." She wasn't alone. Her oncologist, breast cancer expert John Fetting, had the same realization.

In the decades Dr. Fetting has been treating breast cancer patients, he has



From left, Carly Ries, Leslie Ries, Emily Ries

"There has to be a better way than cutting off body parts."

— CARLY RIES

seen and been affected by the limitations of treatment. Even with major advances, too many patients are not cured and die of breast cancer, he says.

"After trying to cure patients with breast cancer for 30 years, we need to implement another approach in our battle," says Fetting. "For all of the success of treatment, the experience is punishing and leaves physical and emotional scars. After treatment, survivors and their family members live with fear of recurrence, and their lives are forever different."

Among these tolls is the threat of breast cancer that looms so heavily over so many families, including that of Leslie and her husband Tom. In honor of Dr. Fetting, they gave a lead gift in 2011 to start the John Fetting Fund for Breast Cancer Prevention to move prevention to the forefront of breast cancer research. Using the latest technological advances, the team of Johns Hopkins experts in breast cancer and genetics is committed to developing better options

for families who have already been touched by breast cancer as well as for others who may not even know that they are at high risk.

Leslie and Tom's daughter Emily calls herself a pre-vivor. She has the same BRCA mutation as her mother, and that puts her at much greater risk for breast and ovarian cancer. For many women who inherit a BRCA mutation, it's not a matter of "if" they develop breast cancer but "when" they develop breast cancer.

She can still recall the pain at 21 of learning about her mother's breast cancer diagnosis. At that time, her mind was focused on the unthinkable possibility of losing her mother. "I wondered, what if she's not there when I get married or have kids," says Emily. She wasn't yet aware of what lay ahead for her or the cruel reach of breast cancer.

When genetic testing showed that Emily inherited the BRCA mutation, she'd hoped less invasive ways of cancer prevention would become

available before she had to take action. She didn't want cancer to be her legacy. Now, in her 30s, married and the mother of a young son, the thought of not being around to see him grow up weighed too heavily on her to wait for those advances. Yet to do the most she could do to try to prevent breast cancer, the options were strikingly similar to her mother's options, though without the need to have chemotherapy. She made the difficult decision to have a double mastectomy. The night before her surgery, she recalls looking at her perfectly healthy, unscarred breasts wondering why the best prevention available to her was lopping off body parts.

This was just the beginning for Emily. She had more surgeries over two years, including a hysterectomy and oophorectomy to remove her uterus and ovaries to prevent other cancers caused by the BRCA mutations. She has a hormone patch that helps ease the symptoms of the resulting early onset of menopause. The surgery means Emily and her husband cannot grow their family, but eases some of the worry that she won't be around to see her son grow up.

Leslie and Tom's daughter Carly was just 17 years old, a high school senior, when her mother was diagnosed. Like her sister Emily, she has inherited the BRCA mutation. For now, at 32, Carly has chosen surveillance, close monitoring aimed at early detection.

"I totally understand and support the decision my sister made, but for me, at this stage of my life, I want to wait until I have children before I move forward with cancer-preventive surgery," says Carly.

**ROUGHLY 30% OF BREAST CANCER CASES COULD BE PREVENTED BY MODIFYING KNOWN RISK FACTORS**

The heartbreak is that she has to think about this at all. The Fetting Fund's goal is to change this trajectory through research.

"This was a pivotal time in my life and my sister's life. Emily was about to graduate college, and I was graduating from high school," Carly remembers. "I don't want to live my life scared." Carly's hope is for progress that will mean one day women won't be confronted with decisions like these.

It's a lot for a young woman to take

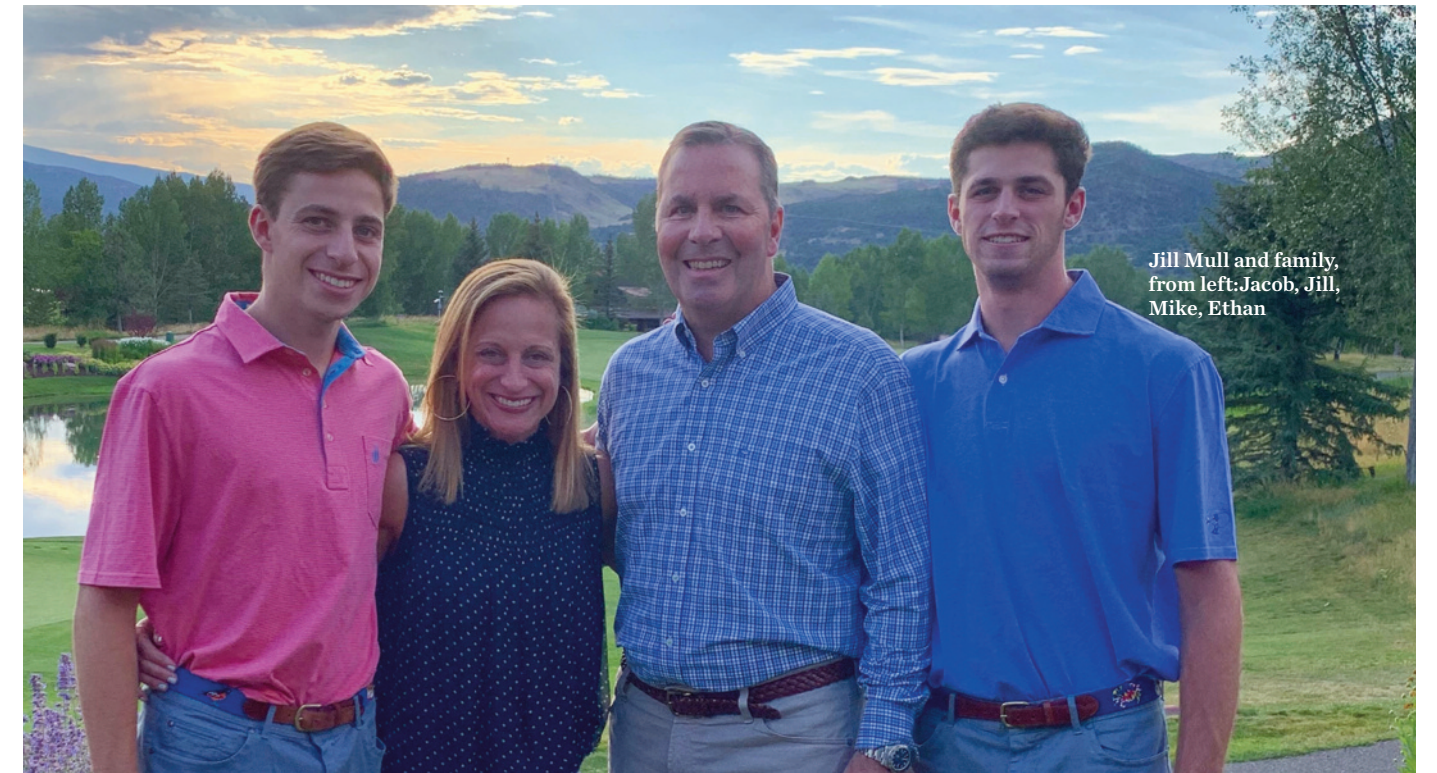
on, yet Emily and Carly consider themselves lucky. "I got to make my own decisions. I didn't have to wait to have cancer, but what a choice to have to make," says Emily. Carly agrees. She says, "There has to be a better way than cutting off body parts." That better way she hopes will come from the research the Fetting Fund is making possible.

Fetting's goal, shared by the Ries family and the patients, families and others who support the Fetting Fund, is to bring an end to these kinds of agonizing decisions and the trauma of breast cancer by shifting the focus from cure alone to cure and prevention.

As Leslie and Tom's daughter Carly continues to think about the unthinkable and whether her only option for breast cancer prevention will be to have healthy body parts removed so they don't become cancer later, she volunteers for studies, donating blood samples. Like her sister Emily, she hopes researchers can use them to unravel the very origins of breast cancer and find better ways to prevent breast cancer in the future. It would be ideal if these answers came before Carly has to make a decision about surgery. She understands the timing might not work out. "I may not see the benefits, but someone will in the future, and that's important," says Carly.

Lorraine Schapiro understands. Breast cancer abruptly entered her life 14 years ago when her daughter Jill Mull was diagnosed. When she heard about the Fetting Fund, she and her husband Mark joined the cause without hesitation. Prevention was already on Lorraine's mind. "We hear so much about cure, and I thought what about prevention?"

Tears still fill Lorraine's eyes when she recalls the day she received the call from Jill delivering the shocking news that she had breast cancer. As the reality sank in and Jill underwent a lumpectomy to remove the cancerous tumor, Lorraine says, "I remember thinking, please don't let it be in her lymph nodes." The pathology from the lumpectomy found unclear margins between cancer and normal cells,



Jill Mull and family, from left: Jacob, Jill, Mike, Ethan

We cut, burn and poison, and even that **doesn't always work forever.** - JILL MULL

meaning the cancer may have begun to spread. Lorraine once again pleaded, "Please don't let her need a mastectomy," but the unclear margins of the cancer required a mastectomy. "Please don't let her need chemotherapy," Lorraine thought, but Jill's cancer required six months of chemotherapy and an additional nine months of treatment with the drug Herceptin and 10 years of tamoxifen therapy.

Herceptin and tamoxifen are major success stories in the treatment of breast cancer. They block the hormones and other signals that certain types of breast cancers need to grow and spread. These drugs work well, but they cause side effects, and they don't work in every patient.

Jill tried complementary approaches, such as acupuncture to ease her symptoms. Mostly, she is grateful for the support of her family, particularly her husband Mike.

A little laughter helped as well.

When she lost her hair during chemotherapy, her son announced to his kindergarten class that Jill was bald. Later, when she was having her mastectomy, he told his teacher that his mommy was having her boobies thrown in the trashcan because they were very bad.

Funny yes, but also a sober reminder of the intrusion of breast cancer into too many families.

Jill was diagnosed at just 32 years old. For the young mother of 4-year old twin boys, breast cancer was the last thing she was expecting, but she remained positive, never asking "Why me?" Lorraine, on the other hand, recalls being in denial, certain Jill's abnormal mammogram was just a mistake. Lorraine was in a Pilates class and didn't answer the phone when Jill first called. When the phone immediately rang again, Lorraine instantly knew. Her heart filled with dread and she answered. "It was devastating,"

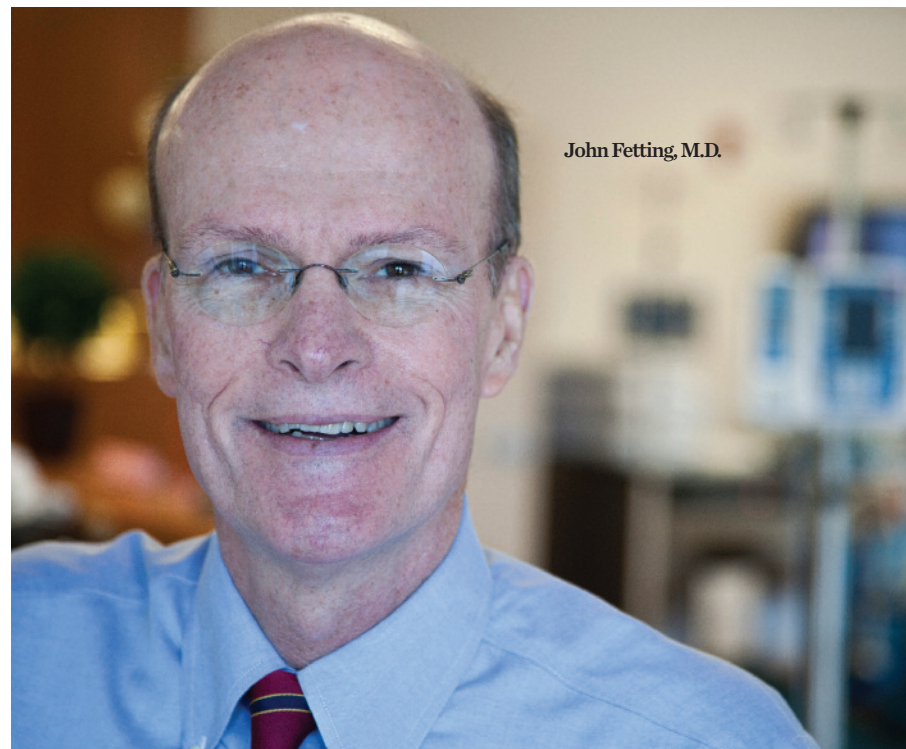
Lorraine says. She credits Dr. Fetting with getting them both through the diagnosis, treatment and recovery.

Genetic testing revealed that Jill had not inherited a BRCA mutation. There was no answer for why she developed breast cancer at such an early age. Whether there were genetic clues that could have predicted and prevented it is the type of research the Fetting Fund supports.

**AN ESTIMATED 232,000 NEW BREAST CANCER CASES ARE DIAGNOSED IN THE UNITED STATES EACH YEAR**

"We are in the process of identifying genetic changes in breast tissue that convert normal cells to cancer cells. I believe we can figure out which changes are necessary for breast cancer to develop and intervene," says Fetting.

When Jill realized breast cancer was going to be a part of her life, she turned it into a way to help other patients, joining the Breast Cancer Pro-



John Fetting, M.D.



Jill Mull with her mother, Lorraine Schapiro

GENETIC TESTING REVEALED THAT JILL HAD NOT INHERITED A BRCA MUTATION. **THERE WAS NO ANSWER** FOR WHY SHE DEVELOPED BREAST CANCER AT SUCH AN EARLY AGE. WHETHER THERE WERE GENETIC CLUES THAT COULD HAVE PREDICTED AND PREVENTED IT IS THE TYPE OF RESEARCH THE FETTING FUND SUPPORTS.

gram at the Johns Hopkins Kimmel Cancer Center as a patient navigator for newly diagnosed patients with breast cancer. Her focus is on patients under age 50.

Sharing her story brings them hope. They see a survivor in her. She sees a bigger need in them. She has seen too many young women lose their lives to breast cancer, and she yearns for the day when she doesn't have to sit with women as they write letters for their children to open on special occasions in their lives—birthdays, graduations, weddings, births—because their mothers may not be there. For Jill, Fetting Fund research is the key to changing this reality.

“We cut, burn and poison, and even that doesn't always work forever,” says Jill.

Erin Yale is among the women who remind us of the limitations of treatment, even when it is diagnosed early. Erin was supposed to be one of the lucky ones. Her breast cancer was detected in what is considered a curable stage.

In 2012, at age 30, she nursed her newborn baby for the last time before she went to the operating room for a mastectomy. After learning she inherited a BRCA mutation, she had surgery to remove her fallopian tubes and ovaries in 2014 to ward off cancer.

Erin recalled in a video made of her talk at a 2018 Fetting Fund event that, as the years passed, she tried to return to her normal life as a young wife and mother, working in the corporate world and launching Pushing Pink Elephants, a breast cancer awareness and educa-

tion endeavor focused on a better understanding of prevention, health and wellbeing. “Normal,” however is relative, Erin pointed out. “The weight of recurrence never goes away no matter how well you feel.”

Erin had surgery, chemotherapy, radiation therapy and hormone therapy—everything doctors have in their arsenal to fight breast cancer and still, in 2017 she learned her cancer had returned and spread throughout her body. There would be no cure for Erin, who passed away in 2019 at 38, leaving behind her devoted husband Steve and their 8-year-old-daughter.

Erin, a Fetting Fund advocate, left a powerful message, “Early detection does not necessarily mean survival or better outcomes. I was diagnosed at Stage 2, and it still advanced to the worst stage,” she said. “We can make a difference in the world. We need prevention. We need the Fetting Fund so people don't go through what I went through. I don't want that for my daughter.”

Her call is championed by Fetting, Leslie and Tom, Emily, Carly, Jill and Mike, Lorraine and Mark, and echoed by women and families around the world.

As the Fetting Fund pioneers a new way of thinking about breast cancer care, it is an uphill battle, as the lion's share of research dollars go to study new therapies. Stories like these are inspiring change, however, and the early success of Fetting Fund research shows what is possible through prevention.

**ROUGHLY 40,000 WOMEN DIE IN THE UNITED STATES FROM BREAST CANCER EACH YEAR**

“We know it will not be easy, but this cannot continue,” says Fetting. “We need the same kind of concerted effort for prevention that has been mounted to treat breast cancer.”

The Fetting Fund is investigating the scientific benefits of natural remedies such as the spice curcumin, broccoli sprouts tea and a magnolia tree extract that may contain properties that detoxify carcinogens or reset the molecular errors that initiate breast cancer. Technological



Erin Yale with her family



“We need prevention. We need the Fetting Fund so people don't go through what I went through. **I don't want that for my daughter.**”

- ERIN YALE, 1981-2019

advances mean we no longer have to wait until a cancer is visible through imaging or a lump can be felt to detect it. New molecular tests that make the invisible visible can detect early changes that precede breast cancer. This includes understanding the connection between genetic and epigenetic (reversible chemical changes to DNA) that contribute to breast and other cancers. Then, injecting anticancer drugs or a drug like tamoxifen directly into the breast ducts could eliminate these changes before a cancer has a chance to grow. Vaccines that train the immune system to patrol and destroy breast cancer cells are another promising area of study. Lifestyle research, such as the role of alcohol in promoting breast cancer development, could yield simple changes that can ward off breast cancer.

“This is just the beginning,” says Leslie. “There is so much promise. I can see it, and I feel that it's going to happen.” ●

## THE PATH TOWARD A BETTER WAY

### MISSION OF THE JOHN FETTING FUND FOR BREAST CANCER PREVENTION

The mission of the Fetting Fund is to identify the one woman in eight who is at high risk for developing breast cancer in her lifetime and to develop safe, effective natural products and drugs to prevent that breast cancer. Of equal importance, the research supported by the Fetting Fund seeks to identify the seven in eight women who will not develop breast cancer. Medical caregivers will be able to provide more prevention efforts for those at risk and reassure those who are not.

Traditional funding sources are focused on advances in treatment and the quest for a cure for breast cancer. As a result, funding for prevention research has lagged. The Fetting Fund relies on private philanthropy to support pilot prevention studies that will produce results and allow Johns Hopkins prevention scientists to design more substantial research plans and compete successfully for larger grants. Our vision is to support enough high quality pilot studies that our breast cancer scientists will be able to attract funding for a rich portfolio of large breast cancer prevention studies. The Fetting Fund is a catalyst for development of a critical mass of breast cancer prevention science and breast cancer prevention scientists resulting in a world class breast cancer prevention program at the Johns Hopkins Kimmel Cancer Center.

THE JOHN **fettingfund**  
FOR BREAST CANCER PREVENTION