

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 prevention.

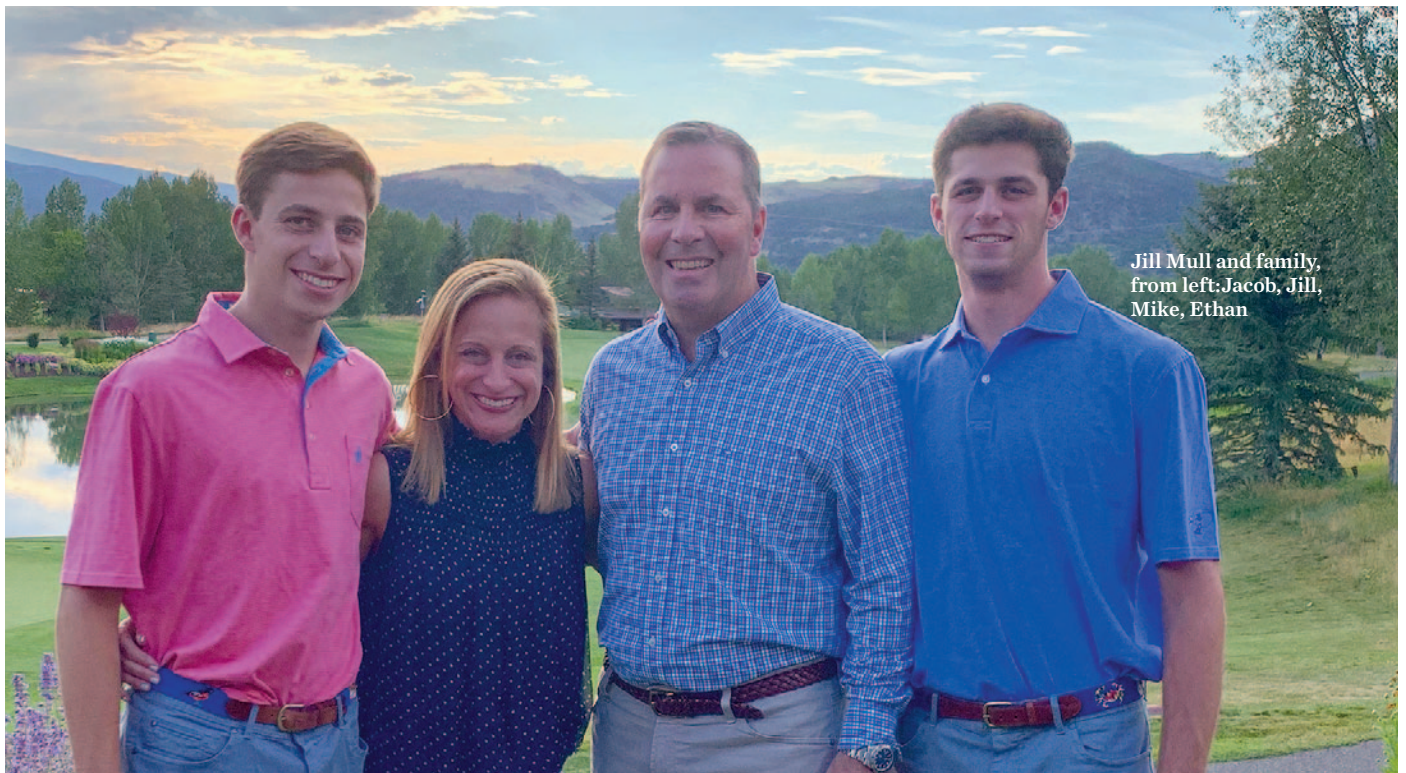
As Leslie and Tom's daughter Carly continues to think about the unthinkable and whether her only option for breast cancer prevention will be to have healthy body parts removed so they don't become cancer later, she volunteers for studies, donating blood samples. Like her sister Emily, she hopes researchers 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,



John Fetting, M.D.



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-



Jill Mull with her mother, Lorraine Schapiro

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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