



The Brightened & Enlightened Series Presents *FORCE*

Cancer Wellness is proud to present the first installment of our new series in partnership with Bright Pink. FORCE is the first (and largest) nonprofit focused on providing education and resources to the hereditary cancer community, while championing efforts to widen access to genetic testing, cancer screenings and lifesaving treatments and procedures — regardless of income or insurance status.

BY CATHERINE EVES

Photos provided by FORCE



“Hereditary cancer is a lifelong struggle,” says Verinda Hobbs. “It’s like a time bomb, and [you] don’t know when something might happen, if you’re carrying that gene.” Hobbs is the partnerships and diversity manager at FORCE, AKA Facing Our Risk of Cancer Empowered — a nonprofit whose mission is to improve the lives of all individuals and families with hereditary predispositions to cancer, regardless of income or insurance status, by providing access to education, genetic counseling, testing, screening and preventative services.

Hobbs, like most of FORCE’s staff, has a family history of hereditary cancer. When her sister was just 28 years old, she was diagnosed with breast cancer. Only four years after that, she was gone. “At that time [in 1998], we didn’t know much about genetic connections to cancer [and] we couldn’t find a lot of support, so that became a difficult time in my life,” says Hobbs.

With little support from medical professionals, Hobbs’ family had no idea that one of their own passed from a cancer foretold in her very DNA — a genetic mutation that had been there since birth. They had no idea that there were most likely other family members that also carried this mutation, or that, once made aware, there were steps they could take to decrease their risk of contracting hereditary cancer. It sounds alarming, but this is a fact for many families across the world, which is exactly what Sue Friedman aimed to address when she founded FORCE more than 20 years ago, on the cusp of the new millennium. *(Story continues on next page.)*



Since 2007, Bright Pink has been a national leader in educating, equipping and empowering millions of women to be proactive with their breast and ovarian health. Today, Bright Pink operates as a nonprofit venture philanthropy fund, building on their proven success and deep expertise to find and fund the next generation of groundbreaking breast and ovarian health initiatives. Laser focused on moving the needle on young women’s breast and ovarian health outcomes, Bright Pink has continued to deepen its focus on health equity and finding solutions that remove barriers to care and help save lives. Why? Because despite advancements, millions of women continue to needlessly die of breast and ovarian cancer every year.

Cancer Wellness is partnering with Bright Pink to highlight their Mission Partners — nonprofits that embrace evidence-based practices, make steadfast commitments to ensure health equity and are working toward a common goal. Together, Bright Pink and their Mission Partners have the power to develop systemic change.

That’s why Cancer Wellness and Bright Pink are pleased to announce the “Brightened & Enlightened Series.” Each issue, Cancer Wellness will sit down with officers and executives from one of Bright Pink’s Mission Partners to highlight their triumphs in the cancer prevention space.

The Winter 2022 issue features the faces behind FORCE — Facing Hereditary Cancer Empowered. As a Bright Pink Mission Partner, FORCE aims to deliver greater coverage of preventative care for underserved high-risk women by improving state legislation. Bright Pink will support FORCE in recruiting, training and equipping a diverse cohort of patient advocates to break down barriers to preventative care at the state level.

Friedman, who today acts as FORCE's executive director, was 29 when she was diagnosed with breast cancer. She had a one-year-old baby and was preparing to get pregnant again, when she found a lump. It was 1996, and the BRCA1 and 2 mutations had just been isolated as breast cancer susceptibility genes, and the screening for this mutation had just become the first available genetic test for cancer risk. But despite Friedman's medical training as a veterinarian and her experience going through cancer treatment and surgery, the first time she heard about the BRCA mutation was while she was waiting for a fitting at a local mastectomy boutique.

After her fitting, she went home and started researching, and realized that she matched many of the descriptors of individuals with the BRCA mutation — the most eye-opening being that her Ashkenazi Jewish heritage meant that she was at increased risk. According to the CDC, one in 40 Ashkenazi Jewish women have the BRCA mutation, but in the general population, it's only about one in 500 women.

Then Friedman's cancer came back. Following this recurrence, she knew she had to be proactive about her own health, so she underwent a full hysterectomy following the birth of her second child. "I was newly menopausal; I had all these other issues about risk, about my family, about menopause, and they were different than the other breast cancer survivors I was meeting," Friedman says. It was 1998, and Friedman was active on a message board for breast cancer survivors. "I'd post I have this mutation, and people were like 'What's that?' because it was still new, and I started meeting these other people who said, 'I probably don't belong here, I don't have cancer, but I have this gene,'" Friedman remembers. She found a lot of like-minded individuals, who hadn't had cancer themselves but were caregivers of people who did, or who were also searching for answers about what is today known as hereditary cancer. Friedman found that many of them felt either unwelcome or uncomfortable taking up space in a corner of the internet devoted to people going through treatment.

"It was really those people who didn't feel welcomed anywhere that I thought needed a home. That's why I started FORCE," she says. "We were really grassroots, but it grew quickly because there was a need and a gap." Growth was so exponential because FORCE was the only organization at the time serving the hereditary cancer community, which is linked to breast, ovarian, pancreatic, prostate, colorectal and endometrial cancers. FORCE was founded during a time when significant strides in cancer research were being made, especially regarding these mutations, or cancer susceptibility genes. As well, improving technology meant that screenings were becoming less cost-prohibitive and therefore more accessible, to an extent. But with better access came more questions, and FORCE wanted to be able to provide those answers.

That's why Verinda Hobbs, like many before her, was recommended to reach out to FORCE. Their resources provided the clarity and calm Hobbs needed while her family was grieving the loss of Hobbs' sister. Hobbs found FORCE's community support resources especially welcoming. "They had support groups that could help me understand what was going on, deal with the grief of my sister, and understand what the future held," Hobbs says. "The support and encouragement I got from the women and some men [...] really struck a chord in me and made me feel understood in a way that I had not been before."

That's why Hobbs jumped at the opportunity to join FORCE's staff. "I don't want to see anyone else's family go through that type of struggle — looking for information, being turned away," she says. "People of color, particularly with breast cancer, when it's diagnosed it's at an aggressive stage, so timing is of the essence, [and] not knowing what to do next is a terrifying position to be in. [...] FORCE is able [to] bring comfort, information, resources [that] help people like me, that didn't have those resources at a time we really could have benefited from them. That's why I'm here and why I do what I do."

FORCE's senior vice president of volunteer programs, Sandy Cohen, has a similar story. She originally connected with the organization after finding out she was a carrier of the BRCA mutation. Cohen's grandmother passed away from breast cancer when she was only 38, and Cohen's mother expressed worries that she herself would also get cancer. "This was all before the genetic mutations were found, so she didn't know there was a real link, but she felt something inside of her and it stayed with me," Cohen says. After her mother passed away at the age of 54, also from breast cancer, the fear of a hereditary link was cemented in Cohen herself. "I became obsessed with thinking about it right after my twins were born. I thought, 'I can't leave these babies,' so I had the testing, it came back positive, and my genetic counselor pointed me in the direction of FORCE," she says.

From her start running FORCE support meetings in the Philadelphia area to assuming her current role at the organization, Cohen has found the experience to be invaluable. "[FORCE] empowered me with information. They comforted me because they understood what I was about to face," she says. "It was so nice to be validated and to be amongst peers who understood and shared some of their decision making, [so] I too felt comfortable with how I wanted to manage my own risk."

FORCE has 12 different support groups available to the hereditary cancer community — there are so many, because a major facet of their overall mission is to address the unique needs of everyone who makes up the hereditary cancer community. Following the pandemic, FORCE pivoted to a virtual format for all their support groups, meaning location no longer inhibits access to support. They have a group that is conducted in American Sign Language, one for caregivers and parents, one for the LGBTQIA community, one for young cancer survivors, and eight other types that are each tailored to serve a unique corner of the community.

FORCE knows they can only measure their success by how they support those who are most underserved, meaning their advocacy and public policy efforts are a vital part of the organization. Currently, most health insurers don't provide adequate coverage of screening and prevention services for those considered high risk. Friedman, FORCE's founder and executive director, notes that specific communities are affected by hereditary cancers at higher rates than the general population (such as the rates of BRCA 1 and 2 mutations in Ashkenazi Jews), which FORCE addresses by mobilizing volunteers to become Patient Advocate Leaders, or PALs. PALs put in the work to actually influence national legislation in order to widen access to these services for all communities facing hereditary cancer. "A lot of people don't have adequate insurance coverage, or the insurance companies in their states don't cover the surgery that's required to help them stay alive or prevent cancer from becoming overwhelming in their family and their own lives," says Hobbs.

FORCE's PALs also work to advocate for more diversity in scientific research. "We see a lot of the ways that lack of inclusion and diversity in research can lead to gaps in guidelines," Friedman says. "We did an XRAY review, looking at [how] some research studies are designed in a way that who's excluded from the research can add to disparities," she says, noting that certain comorbidities may be more prevalent in people of color, for example. "If that's the case, if that's an exclusion, then when you get results [they] may not [apply to] diverse populations."

FORCE's website features many tools available to people seeking insight about hereditary cancer — along with details about their public policy and advocacy efforts the site also features information about clinical trials, how to find financial assistance and how to connect with a Peer Navigator volunteer — someone who shares a similar situation and can offer support. The site also provides access to the XRAY program. "[We're] trying to address online digital health literacy, and really trying to help people understand where to find reliable information online," Freidman says, noting how easy it is for people to spread misinformation. FORCE's XRAY program offers an extensive database of research that is delivered in language anyone can understand, bridging the gap between the science as it's reported in peer-reviewed journal articles and the general population.

The hereditary cancer community is only growing, and FORCE adapts to that by continuing to expand their coverage to include information and resources for new mutations and communities as they become known. They've just recently added Lynch syndrome to the roster, for example, which comes with an increased risk for colorectal, endometrial and other cancers. This commitment to serve the ever-widening hereditary cancer community is how FORCE has made itself such a powerful... well, force... in the hereditary cancer community. "We have to stop making it such a burden on people to be able to take care of themselves and their families," says Hobbs. "Our main goal is to make sure no one has to face hereditary cancer alone," adds Cohen.

To learn more about FORCE or to join their volunteer program, visit FacingOurRisk.org



FORCE

Facing Hereditary Cancer EMPOWERED

