FORCE Celebrates a Decade of Service

by Sue Friedman

New Year’s Day 2009 marks a special milestone for FORCE and for me. Twelve years ago when I went through cancer diagnosis and treatment and learned that my cancer was hereditary, I felt alone and scared. At a time when I should have been enjoying my marriage, a new baby, and a burgeoning career as a veterinarian, I was diagnosed “out of the blue” with breast cancer.

During treatment I learned that my breast cancer at age 33 was anything but out of the blue; instead it was caused by a BRCA2 mutation I inherited. Facing difficult decisions and trying to research my options, I had no trusted resource for all the information and support I needed. And so, on New Year’s Day 1999 I posted my first online message, inviting others who had a hereditary cancer or a BRCA mutation to join me. Within minutes I saw a response to my post on the message boards—that represented the first FORCE program, and with those initial keystrokes the FORCE community was born. In the ten years that followed I have made friends and connected with a community that can only be described as my extended family.

A decade has gone by so quickly. We have grown into the foremost advocacy and support organization for our community. We have programs and resources that address every aspect of hereditary breast and ovarian cancer, and reach community members across the country and around the world. And we have been a FORCE for change. Together with your help we have accomplished the extraordinary: we’ve put hereditary breast and ovarian cancer on the map.

FORCE participated in the advocacy efforts that led to passing of the Genetic Information Nondiscrimination Act, federal legislation that becomes effective this year to prohibit discrimination based on a genetic test. We were also staunch advocates for Johanna’s Law, which promotes education and awareness about ovarian cancer risks and symptoms. By introducing and promoting the label previvor, we created a forum for high-risk individuals and established their role as important stakeholders regarding cancer research and resources. By connecting with our community through our website, face-to-face groups, surveys, and annual conference, we are setting a national hereditary cancer research agenda with your input, to help guide our research collaborators.

Over the last decade we have educated hundreds of thousands of people about the latest advancements in cancer prevention, detection, treatment, breast reconstruction, and quality-of-life issues specific to hereditary cancer. Our in-person outreach has expanded to almost 50 groups. We provide the largest conference by and for the community affected by hereditary breast and ovarian cancer.

With your future support and involvement, we will continue to grow and promote awareness, resources, education, research, advocacy, and support until the day we are no longer needed. As we frequently say on the FORCE message boards, we are sorry that members of our community have cause to need us, but we are very happy that you have found us, and that we are here for you.

Happy Anniversary, FORCE!
2009 Joining FORCEnes: 4th Annual Conference Bigger and Better

by Sue Friedman

We couldn’t be happier about the growth of our past three conferences. In fact, we’re moving our May 15-16, 2009 Joining FORCEnes Conference to the Buena Vista Palace Hotel and Spa in Orlando to accommodate more than 500 previvors, survivors and health care providers. We’re planning something for everyone, including exciting new sessions:

• The latest research on improving health with exercise, nutrition, and lifestyle changes.
• Author and humorist Pat McRec will show how laughter can help deal with a crisis.
• Cutting-edge techniques for prevention and detection of breast and ovarian cancer.
• Sessions specifically for healthcare providers and advocates focused on reaching underserved members of the high-risk community.
• Special networking sessions for men at high risk, spouses, and partners.

Many of our most popular sessions will also return, including:

• Our workshop for young women at high risk.
• How to discuss risk with children.
• Understanding mastectomy and breast reconstruction.

Joining FORCEnes is a unique opportunity to learn about risk, what it means to live with BRCA, and how to understand and manage your options. The conference is also about networking, offering extraordinary opportunities to speak one-on-one with leading researchers, health care professionals, and other members of the BRCA community. So no matter what your interest or personal story, if you, your family or a friend has been affected by hereditary breast or ovarian cancer, come join us and experience the power of the FORCE community.

Join us Thursday evening for our welcome reception. Kickstart your conference experience while you enjoy a 360-degree view of Orlando and the fireworks of Epcot Center from the top floor of our hotel. Bring yourself and your family and join us in Orlando in 2009. Let the magic begin.

Register for our 4th annual Joining FORCEnes conference: visit www.facingourrisk.org/conference.

Comments from the 2008 Joining FORCEnes Conference

“I went to the conference to observe, learn and grow as a professional, but I also grew as a person. I hope other genetic counselors will attend; it is truly an educational experience not taught in text books.”

“I would sum up attending your conference as they do with that credit card commercial: in one word...PRICELESS!”
Raychel’s Story: I Will Previve

by Raychel Kubby Adler

I have always felt as if I have a target on my back. A big red cancer bullseye.

Most days it is just there, somewhere in my subconscious, and then there are the other days. The day the mammogram technician kept taking picture after picture of the same square inch of my left breast. All of the days when I listed my health history and the litany of close relations with cancer: mother, sister, grandmothers, cousins. The days I talked with my sister, who although 16 years my elder, was my genetic match and suffering from metastatic breast cancer.

I remember my surprise one day when I caught myself saying “when I get cancer.” So after having children and finishing nursing, I decided to pursue genetic testing. My sister who was positive for a BRCA2 mutation always wanted this for me. She felt since she could no longer save herself, it was her duty to help me help myself. Helping me have a different reality/destiny then her own was her only chance to do something differently.

I made an appointment with a genetic counselor without thinking much of it. The possibility of testing negative never occurred to me. The day I received my results the target moved front and center. My positive result was validation of what I already knew, and in some ways, motivation to do something differently.

I remember the genetic counselor saying something about how sometimes women’s quality of life takes a dip after getting a positive result, but that one year later most women found they had an even higher quality of life then before they tested. I understood she said this to console me, but the idea repelled me. Why did my quality of life need to dip? What if this result could be more like a get-out-of-jail-free card? Why did people look at me after hearing this news as if it were a death sentence? Although statistically I have a very high chance of developing breast cancer, now I could actually do something about it and have my insurance support my choices. Ever the optimist, I left the appointment with a big “to do” list of research, doctors to meet, and choices to make.

In the months following my test, I realized how blessed I am to have a positive mindset and a supportive environment that enable me to move forward full of hope for what lies ahead. I am also lucky to have the resources to navigate and utilize the health insurance and medical world labyrinth.

My experience as a breast cancer previvor brought new focus to my work as a Wellness Coach. Prior to this “health issue” I had always worked with women who wanted to make healthy behavior changes in their nutrition, fitness, stress management, sleep, and life balance. My work in these areas has always remained disparate from my own experience as the caregiver and relative of cancer survivors. For me, being part of FORCE illuminated just how much we all need each other through this process, so that none of us has to feel alone, without resources, or confused about our choices and path to wellness.

Through Wellness Coaching I can help people focus on what they value and desire in terms of health and well-being, and motivate them to understand how to overcome the obstacles they may find in their way. Through FORCE I have the means to help women prevent cancer and to improve the lives of those who already have contact with the disease. These resources are available to anyone who wants to take this next step towards optimal well-being.

Raychel Kubby Adler is a Wellness Coach who helps women make small and meaningful behavior changes so that they can live healthier lives. Raychel is also a breast cancer previvor and uses her own experience to coach cancer survivorship.

What’s a Previvor?

Cancer previvors are individuals who are survivors of a predisposition to cancer but who haven’t had the disease. This group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor. The term specifically applies to the portion of our community that has its own unique needs and concerns separate from the general population, but different from those already diagnosed with cancer.

FORCE coined the term previvor in 2000. Since then, the term has been adopted by many high-risk women, health care providers and researchers, and was named by Time magazine as one of its top 10 buzzwords of 2007.

FORCE continues to work to unite the previvor community and advocate for much-needed resources and research. As more attention and awareness is focused on individuals who live with a high risk for cancer and the difficult decisions they face, more resources will be devoted to this unique and important population.
Voices of FORCE

Each quarter, we’ll invite a FORCE member to share an insightful perspective, a valuable experience, or a touching story to help others who are dealing with issues of hereditary breast and ovarian cancer

The Linda Pedraza Scholarship Fund—My Saving Grace

by Grace Talusan

I was awarded a scholarship in Linda’s honor, which funded my attendance to the FORCE national conference. During that weekend in May, I met my message board friends face-to-face. I attended presentations by top researchers on all aspects of hereditary breast and ovarian cancer.

As a woman of color living in the U.S., whenever I walk into a room, I scan to see if anyone looks like me. I noticed a few women of color at the conference and wished that more were in attendance. Recently, when I learned about research suggesting that the frequency of breast cancer gene mutations in Asian American women is underpredicted, I wondered if there was a connection. Maybe more women of color weren’t at the conference because they hadn’t been tested.

And then, I watched In the Family, a documentary by Joanna Rudnick. And that’s when Linda spoke to me. The film includes an interview with Linda at age 42, when she was diagnosed with ovarian cancer and says, “I’m living proof that the technology doesn’t always catch things.”

Living proof. And then I realized: Linda isn’t living anymore. Like me, Pedraza chose close surveillance. She was being treated for ovarian cancer and doing the recommended surveillance for her breasts every six months. One screening she was fine, and by the next, she was diagnosed with Stage III breast cancer, which ultimately caused her death. Despite all evidence and research that points to surgery as my best option, nothing got through to me until I watched Rudnick’s film. Pedraza says, “Being alive is what matters. And in retrospect, if I could have turned the clock back, I would’ve had all those surgeries. It may not be the ideal life, but it is life. You don’t mess with that.”

Last December, both my breasts were removed. In the next few years, before I turn 40, my ovaries will also be taken. My beloved body parts may be gone, but I will still be here.

Grace Talusan (www.gracetalusan.com) teaches writing at Tufts University and Grub Street.

Joining FORCEs

BrCA Mutations (continued)

group, both models were well off the mark. Forty-nine Asian women tested positive for a BRCA mutation, while the BRCA PRO model predicted only 25 and the Myriad II model predicted just 26 women.

How do we interpret the findings?

Since the BRCA PRO and Myriad II models often play an important part in determining whether a person will benefit from testing or not (and may determine whether insurance will pay for testing), inaccurately predicting the number of Asian Americans with mutations may mean that genetic testing is recommended for this community less often than it should be. This denies individuals the opportunity to obtain an accurate estimate of their genetic risk for developing breast and ovarian cancer.

The study suggests that a more effective model is needed for estimating the risk for a BRCA mutation in Asian American women. In the meantime, Asian American women who believe they may be at higher risk should consult with a cancer genetics expert.

Cara resides in Philadelphia and works as an editorial intern. She plans to attend graduate school for journalism and aspires to work one day for National Public Radio.

Reference


Prevalence of BRCA Mutations Underestimated in Asian American Women

by Sue Friedman and Cara Scharf

Not all ethnic groups carry the same risks for inherited diseases. People of African American descent, for example, are at much higher risk for sickle-cell anemia, and people of Jewish background have a higher likelihood of Tay-Sachs disease. We also know that people of Eastern European Jewish descent are 10 times more likely to carry a BRCA mutation than individuals of other ethnic backgrounds. Much less is known, however, about the prevalence of BRCA mutations in other minority groups in the U.S.

Genetic testing for hereditary breast and ovarian cancer is not always a simple, straightforward test, and not everyone will benefit from genetic testing. Meeting with a genetics counselor is an important step to determine whether cancer in a family is hereditary. Counselors use pre-established computer prediction models to estimate a person’s chance of carrying a BRCA mutation and to determine who should be tested. Yet a new study published by researchers from the U.S. and Canada suggests that existing models underestimate the prevalence of BRCA mutations in Asian American women.

Details of the study

Researchers studied BRCA PRO and Myriad II, two models widely used by genetics experts to estimate the likelihood of a mutation within a group of people. Using test information from 200 Asian American women, the researchers ran both models and compared the results with a control group of 200 non-Jewish Caucasian women who had known BRCA mutations.

As expected, the models accurately predicted the number of non-Jewish Caucasian women who had a BRCA mutation. But in the Asian American group, both models were well off the mark. Forty-nine Asian women tested positive for a BRCA mutation, while the BRCA PRO model predicted only 25 and the Myriad II model predicted just 26 women.

Driving to my appointment, I convinced myself the test would be negative. My family had experienced enough bad luck with cancer. My two-year-old niece had battled a rare eye cancer, my aunts had died of breast and ovarian cancers, and my sister and first cousins were being treated for breast cancer. It would only be cosmic fairness for me to test negative. Wishful thinking.

I looked forward to my meeting with my genetic counselor. Like me, she was Asian American. At our first meeting, when she laid out the choices—to test or not to test—I felt very comfortable with her as if I was speaking to a cousin or a sister. I enjoyed this woman’s company until I heard her say, “You’re positive for the gene mutation.” I burst into tears. “You didn’t expect to be positive,” she said. I shook my head. She handed me a FORCE brochure. I left my first message on the FORCE message boards that night and within hours, felt held by the warm hands of our community.

A few months later, my physician explained what I could do with this predictive knowledge. I was impressed with diagnostic technology. MRIs and digital mammograms. If I had cancer, we would find it early. Surveillance might detect cancer, my doctor advised, but wouldn’t prevent it. “I’m comfortable with that,” I said. All the while, my FORCE friends were there for every question and concern. I didn’t sense any criticism or judgment for choosing surveillance.

Although I’d seen the effects of cancer up close, I wasn’t fully convinced of its power. Mary spent the first year of her son’s life prone on a couch, flattened by chemotherapy. She left her first birthday party in an ambulance, and she was in the hospital while I watched him take his first steps. My cousin was pregnant when she was diagnosed with breast cancer, which has since spread to her brain. None of this was enough to convince me to do anything but surveillance.

Then I met Linda Pedraza.
More About Fanconi Anemia

by Margaret Snow

Fanconi Anemia is a rare inherited disorder that can affect children. Children with FA have bone marrow that doesn’t produce enough blood cells. Several genes have been associated with FA, including the BRCA2 gene. A child must inherit two abnormal BRCA2 mutations—one from each parent—to develop FA.

Some children with FA have physical abnormalities such as alterations in skin pigment, deformity of the thumbs, a very small head size, or short stature. Other abnormalities in the heart, kidney, genitalia or hearing may also develop. Blood abnormalities usually develop before the age of 12, and may include fatigue and paleness, bleeding or bruising problems from low platelets, or susceptibility to infections from low numbers of white blood cells. The diagnosis of aplastic anemia is confirmed by a bone marrow biopsy that reveals an abnormally low number of stem cells that make red and white blood cells and platelets.

The risk for two parents carrying an abnormal BRCA gene is highest in couples where one or both of the parents are of Jewish descent. If you or your partner’s family has a known BRCA2 gene mutation, and you are concerned about the possibility of having a child with FA, please consult with a qualified expert in cancer genetics. You can find a genetics expert in your area by visiting the FORCE website. From the left-hand menu, click on “finding health care,” then click on “finding specialists.”

BRCA2 and Fanconi Anemia

by Rachel Altmann

Early one spring morning a baby girl was born. Her parents and her brother had eagerly awaited her arrival. She had a head of black hair with a spiral of white hair by her soft spot. Already in her first days of life the people around her could tell she was both sweet and strong. They could also tell that she had a variety of medical problems, although they didn’t know why. By the time she was a year old she had seen numerous specialists and had four surgeries to correct many of her identified medical problems, but it wasn’t until she was almost two years old that her parents learned that she had a rare and life-threatening disease called Fanconi Anemia (FA). Her name was Nina and she was my daughter.

How did Nina get this very rare childhood disease? Unbeknownst to me and her father, we both carry BRCA2 mutations. Our little girl received one mutated BRCA2 gene from each of us. Her FA is an inherited anemia that leads to bone marrow failure and/or leukemia and other types of cancer. When both parents have a mutation in the same FA gene, as we do, their children have a 25 percent chance of inheriting the defective gene from both parents. When this happens, the child will have FA.

Being a young BRCA mutation carrier involves many difficult decisions. Should I have prophylactic surgeries, surveillance, or a combination of both? What will my boyfriend think? The issue of childbearing also brings complex decisions: Should I rush childbearing? Does my partner also carry a BRCA mutation? These are important questions, particularly because of the chance of inherited FA.

Although there is no cure for FA, the Fanconi Anemia Research Fund (FARF) has been helping families, educating doctors, and funding research to find a cure for 20 years. Through FARF I have made many friends of parents who are FA carriers. Once they learned they were both carriers (after having a child with FA) they made different decisions about how to proceed with their families. Some chose not to have any more children. Some used a sperm donor or adopted. Others opted for in vitro fertilization with pre-implantation genetic diagnosis or used sampling of the placenta to rule out FA early in the pregnancy. There is no right answer. The choices aren’t easy. Everyone must do what feels right to him or her.

Remember that the E in FORCE represents empowered. With information you are empowered to make the decisions you need to make. You can learn more about FA by visiting www.fanconi.org.

Rachel Altmann lives on a windy farm near Portland, Oregon. She likes to read, write, cook, knit, play music and spend time with her family and friends.

Conference Comments (continued)

“It was absolutely, completely, totally wonderful! Whatever I expected was trumped by what I encountered. Everyone was so open and honest. I became so comfortable talking about my breast cancer and reconstruction that I almost struck up a conversation with a total stranger in the airport ladies room until I realized I was no longer at the conference! I can’t begin to explain what an impact this has had on my life. I hope you realize that you are changing lives!”

“I met so many amazing people at the conference. I feel so completely energized and empowered, and I am so grateful for that.”
FORCE Benefit Night: The Things I Wish My Mother Would Have Told Me

by Lisa Held

“At my grandmother’s funeral, I realize, for the first time, that I am the only surviving woman in my family...”—Mia Perovetz as Rosa in The Things I Wish My Mother Would Have Told Me.

On October 23rd, 70 FORCE members, supporters, and friends came together at Center Stage Theater in Manhattan to connect and witness Mia Perovetz’s one-woman play, The Things I Wish My Mother Would Have Told Me.

Attendees entered the theater to find Mia asleep in a bed center stage. When the lights dimmed, she arose from the bed and began her intensely personal portrayal of watching her mother suffer through and eventually die from breast cancer. Mia’s story alternated between childhood memories of her mother and her own struggle as an adult to cope with the absence of her mother’s presence in her life.

Mia’s journey so poignantly shared from the stage struck a chord with the FORCE audience. Those who had lost loved ones to cancer shared Mia’s agony as she acted out her “silent scream.” Her fears of following in her mother’s footsteps too closely resonated with previvors and survivors alike.

After the play, audience members enjoyed cocktails and dinner, generously donated by The Village Pourhouse. They also had the opportunity to meet and chat with Mia and Joanna Rudnick, producer of the documentary In the Family. Many FORCE volunteers were also on hand, including Executive Director Sue Friedman, Director of Volunteer Programs Barbara Pfeiffer, and our New York outreach coordinators. About $1500 was raised to support our critical programs. A special thanks to Barbara for organizing this evening, and to all who came out to support Mia and FORCE.

Linda Pedraza Memorial Scholarship Fund

Linda Pedraza was a member of the FORCE Board of Directors and a staunch patient advocate for hereditary breast and ovarian cancer. She survived ovarian cancer only to succumb at age 45 of breast cancer.

We have established a scholarship fund in Linda’s name to honor her memory. Scholarships provide airfare, accommodations, and registration to attend our annual Joining FORCEs conference. Scholarships are awarded to applicants based on several factors, including:

- financial need.
- impact of conference attendance on the individual’s personal health care decisions.
- willingness to share conference information with their community.
- willingness and availability to volunteer during or after the conference.

Past scholarship recipients have included previvors, survivors, nurses, genetic counselors, and patient advocates. All donations to this fund provide financial support to people who would otherwise be unable to attend our national conference.

Our 2009 conference will be held May 15-16 in Orlando. To provide donations or apply for a scholarship, please visit www.facingourrisk.org/scholarship. Scholarships are limited, so please apply early. If you do not have Internet access, call 866-288-7475, ext. 1 to receive a printed application.
What’s New @ FORCE

Our Happy Anniversary Book

In honor of our 10th Anniversary, we are creating a book of art and poetry to celebrate our talented community. Visit our website to learn more about the book and how to purchase your own copy of this limited edition.

Our Eighth Annual Chat-a-thon

2 days + 2 nights
4 FORCEx

Join us Friday and Saturday, January 30 and 31, for our around-the-clock online event. Help us raise awareness and needed funds for FORCEx. This annual volunteer-staffed cyber chat is a special opportunity to ask questions, gain information, and meet others who face hereditary cancer issues. Stop by for a few minutes or stay for a few hours. Everyone is welcome. Help us make our chat-a-thon a success:

• Log in to www.chat-a-thon.com to join the discussions.
• Spread the word by chatting up the event to friends, family, and physicians.

Joining FORCEx 2008 Conference Webcast

If you missed our conference in May or you’d like to revisit your favorite presentation or workshop, you can now view a free webcast of select sessions. Just visit www.facingourrisk.org/webcast and quickly register to view webcasts of select presentations from the conference.

Men’s Study

Are you a male member of FORCEx or a male partner of a FORCEx member? If so, please take our survey. Researchers at the Moffitt Cancer Center will use your input to help identify men’s knowledge and attitudes towards issues related to genetics and reproduction. The survey takes just 10 minutes. For more information and to access the survey please visit http://mysurvey.moffitt.org/Checkbox/FORCEMaleSurvey.aspx.

We Want to Hear From You

What’s on your mind? What would most help you understand or cope with issues of prevention, diagnosis or treatment? Perhaps you’ve recently tested positive for a BRCA gene mutation and don’t know where to turn. Maybe you’re dealing with breast or ovarian cancer, or care about someone who is. Send your input, ideas and comments to info@facingourrisk.org or mail to FORCEx, 16057 Tampa Palms Blvd. W. #373, Tampa, FL 33647.

Help FORCE Go Green

Want to save some trees? Help FORCE save dollars? To receive an electronic version of this newsletter rather than a print copy e-mail us at: newsletter@facingourrisk.org. Include your name and city and state in the e-mail.