Welcome: 12 Years Strong and More to Come

Another New Year means another FORCE anniversary. And what a year we had in 2010! Our 5th annual conference was attended by 550 people. We are proud of our role in getting the EARLY Act passed and establishing the first national HBOC week and Previvor Day. FORCE members published three books—Positive Results, Previvors and What We Have—for people with BRCA mutations. And last year, researchers continued work on our behalf, conducting trials of promising PARP Inhibitors and showing that prophylactic oophorectomy improves survival for BRCA mutation carriers. In 2010 we also updated our logo and messages boards, and redesigned our website for even easier navigation. We're also easier to find in person, as our outreach program grew to 68 U.S. groups and one each in Australia and New Zealand.

We expect 2011 to be another banner year for FORCE, and we're excited about sharing it with you. We'll continue to offer information, support and insight to anyone who is touched by hereditary cancer. No matter where you are on the hereditary cancer journey, we encourage you to attend our 6th Joining FORCEs conference in June (read below for program details and more information about our new venue). We hope that 2011 may be the year we have more and better treatment options for hereditary cancers. As new information and updates come in, as always, we will be there to report it for you. Finally, we are very proud to announce publication of not one, but two new FORCE books (see “What's New” on the back page).

Sue

Pack Your Bags, Bring Your Family: It’s Conference Time!

by Sue Friedman

Joining FORCES 2011 (June 23-25 in Orlando) is shaping up to be our best conference yet. It is the single most informative resource about hereditary cancer, and our agenda has something for everyone, including survivors, previvors, supporters and health care providers. Over three days, you'll learn about living with a BRCA mutation or a family history of cancer, making important risk-management decisions, coping before or after treatment or preventative surgery, and much more. Our powerhouse roster of speakers will reveal current information and research results about metastatic breast cancers; hormone receptor positive and triple negative breast cancers; PARP inhibitors for hereditary cancer treatment; menopause management with and without hormones; medications to prevent or lower breast cancer risk; detection and prevention of ovarian, fallopian tube, and breast cancer; screening and long-term follow-up recommendations for detecting cancer after mastectomy and oophorectomy; and the latest information for high-risk men. Our workshops will help you sort through the information and make informed health care decisions. See the FORCE website for a list of all 45 sessions.

You'll find plenty of one-on-one opportunities to speak with our experts, and you'll gain support from networking with others who understand your concerns and will happily share their previvor or survivor experiences with you. Reunite with your FORCE family, meet your online supporters in person, and make new friends with peers who face similar challenges.

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Risk-reducing Surgery Lowers Likelihood of Breast and Ovarian Cancer; Decreases Mortality of BRCA1 and BRCA2 Mutation Carriers.

by Lisa Rezende, PhD

The question haunts all women who learn they carry a BRCA mutation: what do I do now? One choice many women make is to remove their ovaries and/or breasts to reduce their risk of ovarian and breast cancers. While this choice seems like a “no-brainer” to some high-risk women, it is not without controversy, as these surgeries carry risks and consequences. A new study reported in the Journal of the American Medical Association shows that risk-reducing surgeries not only decrease cancer risk but also increase the life span of BRCA1/2 mutation carriers.

Gathering a large cohort of women is critical to address common questions such as “Is one strategy more effective for BRCA1 mutation carriers than BRCA2 mutation carriers?” or “Is one strategy more effective than another in preventing cancer or prolonging survival in mutation carriers?” This published study is particularly meaningful because enough patients participated to allow researchers to analyze the effects of risk-reducing surgeries by mutation status and look at the effect on previvors (unaffected carriers) as well as survivors.

Over 2,000 women participated; about half chose to undergo one or more risk-reducing surgery. The compelling results showed that risk-reducing surgeries significantly reduced cancer diagnoses, and that risk-reducing removal of ovaries lowered cancer-related deaths:

- Risk-reducing mastectomy was associated with a decreased chance of breast cancer in women with BRCA1/2 mutations. None of the study participants were diagnosed with breast cancer in the three years after their mastectomy. In contrast, about 7% of women who did not undergo prophylactic mastectomy were diagnosed with breast cancer in the three years after their mastectomy.
- Risk-reducing removal of ovaries and fallopian tubes lowered the risk of ovarian cancer and primary peritoneal cancer (a cancer closely related to ovarian cancer) in both BRCA1 and BRCA2 mutation carriers. While none of the BRCA2 mutation carriers developed primary peritoneal cancer after surgery, 1.8% of BRCA1 mutation carriers did. This is still a significant reduction in risk from the 7.4% of women who did not undergo prophylactic oophorectomy and were diagnosed with ovarian cancer during the course of the study.
- Removal of ovaries was also associated with a decreased risk of breast cancer in both BRCA1 and BRCA2 mutation carriers who were not previously diagnosed. However, removal of ovaries did not reduce the risk of recurrence in BRCA1 and BRCA2 mutation carriers who were previously diagnosed with breast cancer.

We know that these surgeries reduce risk, but do they extend lives? This study showed that risk-reducing surgeries reduced mortality due to cancer for both BRCA1 and BRCA2 mutation carriers. Prophylactically removing the ovaries was associated with a statistically sig-

“The compelling results showed that risk-reducing surgeries significantly reduced cancer diagnoses, and that risk-reducing removal of ovaries lowered cancer-related deaths.”
In 2002, we established the objective to study why more young black women than Caucasian women develop breast cancer. As a research team with a focus on hereditary cancer, we sought to understand the role of genetic factors in this difference. Since then, we have successfully launched initiatives to educate black women about hereditary breast cancer and have developed additional research studies to learn more about the genetics of breast cancer in black women. We have made a lot of progress in the last decade, but much more needs to be done!

Why are we interested in specifically studying breast cancer in black women? Although their overall rate of breast cancer is lower than white women, a higher number of black women develop breast cancer at earlier ages and tend to have more aggressive forms of the disease. When we began our research, little was known about why these differences exist, and we wanted to change that. An important component of our research was to gain a better understanding of how many black women who develop breast cancer before age 50 carry a BRCA mutation. However, we faced a major hurdle, since few black women utilize clinical genetic counseling and testing services. If we were going to be successful in gaining knowledge about the genetics of breast cancer in this population, we had to deliver these services to our participants as a part of our studies. We did just that, free of charge. As a result of our early efforts, we, along with other U.S. research teams, better understand that differences in breast cancer between black and white women are, in part, related to genetic risk factors.

Our most recent study examined the genes of 46 black women with breast cancer at age 50 or younger. Three of the women tested positive for a BRCA mutation (one had a BRCA1 mutation and two were found to have BRCA2 mutations). When we asked participants about their experience with genetic counseling and testing, 95% indicated they were pleased with their participation, and many felt empowered with the information they gathered. As researchers, we now have a better idea of the prevalence and penetrance of BRCA gene mutations in the black community, but we still have a long way to go.

Our community education and outreach efforts took flight in 2006 after receiving funding through Komen for the Cure. With this new financial support, we formed a partnership with community members and ultimately, a Community Advisory Panel (CAP) was born. This group consists of patient advocates, breast cancer survivors, and healthcare providers, many of whom are members of the black community. Our academic-community partnership played a key role in expanding our research efforts and educational initiatives. In 2007, we named our educational initiative B-GREAT (Breast Cancer Genetics Research and Education in African Americans Team) to symbolize this partnership.

In 2007, through our work with CAP members, we identified a need to increase awareness about hereditary breast and ovarian cancer in the black community. This need fueled the development of an educational brochure about hereditary breast cancer targeting the black community. Based on input from our CAP, as well as the larger community of black breast cancer survivors, we finalized a lay brochure in 2008 that is currently available for general dissemination. In two years, we have distributed over 4,500 of these brochures and look forward to getting many more out there in the coming years.

“...differences in breast cancer between black and white women are, in part, related to genetic risk factors.”

Patrice Fleming is a research coordinator for Moffitt Cancer Center. She is the education and outreach coordinator for the B-GREAT Initiative.

Tuya Pal is a board-certified clinical geneticist at Moffitt Cancer Center, with an interest in the genetics of breast cancer in African American women. Tuya co-directs the B-GREAT Initiative.

Susan Vadaparampil is a behavioral scientist with an interest in uptake and outcomes related to genetic counseling and testing for hereditary breast cancer in minority communities. She co-directs the B-GREAT Initiative.
BRCA in the Jewish Community

by Sue Friedman

People of similar ethnic backgrounds often share a likelihood of developing certain diseases.

In some cases, disease-causing mutations that run in ethnic groups or populations, like those in BRCA1 and BRCA2, are the cause. Hundreds of different BRCA mutations have been identified and found in people of every ethnicity, but some are more common in various groups. People of Ashkenazi (Eastern European) Jewish descent, for example, are more likely to inherit one of three specific BRCA “founder mutations”—roughly 2.5% (one in forty) are estimated to carry one of these mutations. This equates to about a 10-fold higher risk of having a mutation than someone in the general population. Even with this increased risk, however, most Jewish people do not carry a BRCA mutation. About 40% of Jewish women with ovarian/fallopian tube cancer and 20% who have premenopausal breast cancer have a BRCA mutation—a much higher rate than non-Jewish populations.

Because more than 90% of BRCA mutations found in Ashkenazi Jewish individuals are a founder mutation, their testing usually begins with a “Multisite 3” panel. Multisite 3 looks only for the three known founder mutations and is less expensive than the approximate $3,500 cost of full sequencing. When people who are Ashkenazi Jewish on both sides of their family test negative for Multisite 3, they are unlikely to have a mutation elsewhere in the BRCA1 and BRCA2 genes, and insurance may not cover “reflex testing” which includes full sequencing of both the BRCA1 and BRCA2 genes.

It is important for people of all ethnicities and racial backgrounds to be aware of the risk factors and the potential need for genetic counseling and testing. A genetic counselor can review your family history and take your ethnicity or heritage into account to determine whether you’re a candidate for testing, and assure that the appropriate genetic test is ordered.

Voices of FORCE

In each issue, 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.

A Chance Meeting that Changed My Life

by Lita Poehlman

In December 2007 my life was forever changed when my husband and I flew to Israel. I spent the flight talking to another traveler, Judy Ludin. When we met, I knew that I had found someone very special who would impact my life. I was about to learn how true my instincts were.

Judy was traveling with her father, and when I asked why her mom hadn’t joined them, Judy informed me that her mother was recovering from surgery and treatment for ovarian cancer. I told her my baby sister had died of ovarian cancer three years ago and my other sister was fighting a recurrence. Immediately, she asked, “Lita, have you been tested for the BRCA gene mutation?” Surprisingly, with all the cancer in my family and my own complete hysterectomy at age 28, I was unaware of this mutation. Judy explained the connection between BRCA and people of Ashkenazi Jewish descent and urged me to explore testing. She also told me about the FORCE website, and her sister, Debbie, who worked for the organization.

After returning home, I threw myself into researching BRCA testing. I spoke with a genetic counselor and decided to have my blood drawn and tested. My results showed that I carry a BRCA1 mutation. I sent my results and letters from my genetic counselor to all of my first-degree relatives. My daughter tested positive for a BRCA1 mutation and for now, has chosen surveillance and tamoxifen. My two sons have not been tested yet, but they tell me they will. My niece, an amazing young woman who has helped many women through her active outreach in the BRCA Facebook community, also has the same mutation, as does her mom, my sister.

I decided to have prophylactic bilateral mastectomies (PBM) and immediate expander reconstruction. But things didn’t go so well and subsequently, I had two more implant reconstructions which were ultimately replaced with tram flaps. Even at age 68 I feel that all I have been through was worth it just to be on the other side of this mutation and accompanying cancer risk.
Signs of Hereditary Cancer

You or any family member has had:

- breast cancer at age 50 or younger
- breast cancer in both breasts at any age
- both breast and ovarian cancer
- male breast cancer
- ovarian, fallopian tube, or primary peritoneal cancer at any age

More than one family member on the same side of the family has had:

- breast cancer
- ovarian or fallopian tube cancer
- prostate cancer
- pancreatic cancer

Genetic counseling is covered by most types of insurance. To find a genetic counselor in your area, visit the National Society of Genetic Counselors (www.nsgc.org/tabid/69/Default.aspx) or Informed Medical Decisions (www.informeddna.com).

FORCE Brochure for Jewish Women

FORCE’s brochure, “What Every Jewish Woman Should Know About Breast & Ovarian Cancer” contains basic information about genetic counseling and testing for BRCA in Jewish women. View and order the brochure at www.facingourrisk.org/publications.

A Chance Meeting that Changed My Life

by Lita Poehlman

“Even at age 68 I feel that all I have been through was worth it just to be on the other side of this mutation and accompanying cancer risk.”

After my hysterectomy over 40 years ago, my surgeon informed me that he saved my life because my ovaries, tubes, uterus and cervix were pre-cancerous. In 2009, during my PBM post-op appointment, my surgeon explained that my left breast had precancerous changes. Once again I had dodged a huge bullet! Thank you, Judy Ludin, from the bottom of my heart for saving my life.

After my PBM, I occasionally browsed the FORCE website, read the newsletters and appreciated the work that was being done. But it wasn’t until I attended the 2010 conference that FORCE became a force in my life. I had no idea of the magnitude of all the work FORCE does for people like me and the far-reaching effects it has on the BRCA community. I extend my love and gratitude to all involved with running FORCE for their dedication, hard work and love that they give to the community.

Lita is a wife, mother, grandmother and great-grandmother. She lives in Jacksonville, Florida.

Share Your Story

Do you have something to say that may inform our readers or ease their experience? We invite you to share your reflections or personal story about dealing with the issues of hereditary breast or ovarian cancer. Tell us how you feel, how you cope, or what you've learned. E-mail stories of 500-550 words to info@facingourrisk.org or mail to FORCE, 16057 Tampa Palms Blvd. W, Tampa, FL 33647. Please include your name and daytime telephone number so we can contact you if we decide to publish your story in a future issue.
We all benefit from research, but most of us never consider participating. We lead busy lives, are stressed with decisions we must make because of our hereditary predisposition to disease, and sometimes, we’re just scared. Without research, however, we cannot move forward to identify new options for people at high risk or develop newer, improved screening and treatment methods.

An easy (and non-scary) way to participate in research is to sign up for ICARE during the Joining FORCEs Conference. At the ICARE table, you can learn more about the registry, ask questions about your potential participation and the process, and enroll in the research. You can also donate blood to help advance hereditary cancer research. If you are planning to attend the conference, you can help even more by bringing a copy of your BRCA results and your family pedigree with you. If you don’t plan to attend the conference, you can still join by contacting ICARE (ICARE@moffitt.org or 813-745-6446 or toll-free at 888-663-3488 extension 6446).

Christina Bittner, MS is a certified genetic counselor and education and outreach coordinator for ICARE.

Tuya Pal, MD is the Principal Investigator of the ICARE Initiative.

It’s Conference Time! continued

This is a great year to bring your partner, spouse, and children to the conference and make it a family vacation. Our new feature-packed venue—the Hyatt Regency Grand Cypress—has something for everyone in your family and is just a short distance from Disney World, Sea World, Epcot Center and the Wizarding World of Harry Potter. Ranked as a Readers’ Choice Awards top resort by Condé Nast Traveler, the hotel features outstanding amenities. Childcare services and Camp Hyatt are available for an additional charge. Your special conference room rate includes many extras at no additional charge:

- Bicycles of all sizes.
- 14 lighted tennis courts. Cardio-tennis sessions (space is limited).
- An enormous pool with waterfalls and waterslides, and three Jacuzzis.
- Rock-climbing wall.
- Sailboats, kayaks, pedal boats and canoes for cruising the hotel’s private lake.
- A fitness room, saunas and steam rooms.
- Jack Nicklaus Signature Design golf courses (with discounted rates for conferees).
- A 9-hole executive pitch-and-putt course (including free clubs).

We’ve arranged a limited number of rooms at the special conference rate ($109+tax/night), so visit our conference travel page (www.facingourrisk.org/conference/hotel) to book your room now.

Hyatt Regency Grand Cypress
EARLY Act Panel to Develop Messaging and Programs
by Lisa Schlager

The Education and Awareness Requires Learning Young (EARLY) Act introduced by Representative Debbie Wasserman Schultz was passed as part of the Patient Protection and Affordable Care Act (a.k.a. healthcare reform) in March 2010.

“The law also aims to provide support services to young cancer survivors and to educate healthcare professionals...”

The legislation directs the Centers for Disease Control and Prevention (CDC) to develop and implement a national education campaign about the threat breast cancer poses to young women, and the elevated risks of certain populations. Its goal is to increase knowledge of breast health and breast cancer among young women ages 15-44. The law also aims to provide support services to young cancer survivors and to educate healthcare professionals, helping them become more skilled at identifying the threats and warning signs of breast cancer in young women—ultimately leading to early diagnoses and saved lives. Representative Wasserman Schultz emphasizes that the purpose of this law “is not to alarm people, but to educate and to empower young women so that we can reduce the number of fatalities from this horrific disease.”

The federal Advisory Committee on Breast Cancer in Young Women met for the first time earlier this year. This 15-member panel with representatives from the medical and breast cancer communities will design the new programs. FORCE had an opportunity to provide input, and we will continue to monitor the panel's work to ensure that the concerns of the hereditary cancer community are adequately addressed.

Lisa Schlager, a former marketing executive, has been involved with FORCE since 2008. In addition to acting as Outreach Coordinator for our Washington, DC FORCE group, Lisa assists the national organization with advocacy and outreach efforts. She lives in Chevy Chase, MD with her husband and two children.

Spread the Word for FORCE
by Lisa Schlager

So, you know that you have a strong predisposition to cancer due to family history or a diagnosed BRCA mutation. You’ve become educated about your options and the latest research for detection, prevention and treatment. Now what? If you would like to help others navigate the HBOC journey but don’t know where to start, consider these suggestions.

Reach out. Distribute FORCE literature to local oncologists, breast surgeons, OB/GYNs, and other healthcare professionals to make them aware of our programs and resources. Share your story with family, friends, and coworkers. Tell them about HBOC and how FORCE supports the hereditary cancer community. Encourage anyone affected by HBOC to attend our Joining FORCES conference.

Go public. Blog and Twitter about your HBOC or FORCE experience. Pitch a story to your local newspaper, TV, or radio station. Uncomfortable putting yourself in the media? Your local FORCE outreach coordinator can identify individuals who are eager to share their stories.

Fundraise. When you raise money for FORCE, you help the entire hereditary breast and ovarian cancer community. Check out the “How to Help” section of our website for more ideas and our step-by-step “Event in a Box” fundraising guide. We need individual and corporation donations to fund our programs; talk to your employer about a sponsorship or corporate matching program.

Empower yourself while helping to empower FORCE. Raising awareness about FORCE and HBOC can save lives. Spread the word!

Advocating for Metastatic Hereditary Breast Cancer Research

Emerging research suggests that hereditary breast cancer may behave differently and respond to treatment differently than sporadic cancers. We need much more research to develop treatments that are specifically targeted to hereditary cancer; the need is dire for women with metastatic hereditary breast cancer who make up a small subset of the larger breast cancer population.

FORCE is conducting a brief survey of women diagnosed with metastatic hereditary breast cancer to provide insight into this life-threatening disease and to advocate for more research and better treatment options. The survey is open to women who:

* have a BRCA mutation or a family history of breast cancer
* have been diagnosed with stage IV (metastatic) breast cancer

Survey responses are confidential, but respondents have the opportunity to submit contact information if they would like to receive research and program updates. If you meet these criteria please consider taking this survey (www.surveymonkey.com/s/BTZOSJW) and share it with any friends or family who may qualify. Visit our research survey web page (www.facingourrisk.org/surveys) to see if there are other FORCE surveys for which you qualify.

Other active surveys at FORCE include:

* Men with BRCA mutations: Needs assessment and research feasibility
* Survey on experiences with Medicare and other insurance, genetic testing and prophylactic surgery

FORCE brochures can be ordered on our website.
What’s New @ FORCE

Our Sponsors

Your generous donations allow us to provide this newsletter at no charge to people at high-risk. Philanthropic support is critical to FORCE’s survival and ensures our continuing ability to provide publications like our newsletter to our community. Your charitable gift can help save lives—please consider making your gift today! To learn more about helping FORCE, visit www.facingourrisk.org/how_to_help.

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 FORCE, 16057 Tampa Palms Blvd. W., 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.

The Official FORCE Book is Coming!

For over a decade, FORCE has been a trusted source of information, support, and resources for individuals and families affected by hereditary breast and ovarian cancers. For just as long, members have asked when we would package that knowledge and expertise into a book. Now we have! Co-authored by Sue Friedman, Kathy Steligo, and Rebecca Sutphen, MD, Confronting Hereditary Breast and Ovarian Cancer will be published by Johns Hopkins University Press early next year. See our next newsletter for more details.

Show and Tell: the Book

Named for one of the most popular events at our annual conference, our new Show and Tell book will be an invaluable resource for anyone facing mastectomy. Like Life is a Carnival, our 2008 publication of post-mastectomy options, Show and Tell features positive and powerful images of women after mastectomy without reconstruction and with various implant and flap reconstructions. The new publication will include more photos, along with each model's description of her surgery experience, and what she liked or disliked about her outcome. Coming later this year.

FORCE in Your Neighborhood

FORCE’s 70 outreach groups (including Australia and New Zealand) provide in-person support and resources. Our newest groups include:

- Connecticut
- Jacksonville, FL
- Knoxville, TN
- Orlando, FL
- Pittsburgh, PA
- Sacramento, CA
- South Carolina
- South Dakota

We are always looking for enthusiastic volunteers to establish new national and international outreach. Visit our website to find a group in your area (www.facingourrisk.org/groups) or to learn how you can help us help others (www.facingourrisk.org/volunteer).