Welcome

FORCE is making history!

We were the first organization to acknowledge and address the disproportionate cancer burden and unmet needs of those affected by HBOC. Early on, we recognized distinct populations in this high-risk hereditary community: those who had been diagnosed (survivors), and those who had not (previvors). By coining the term “previvor,” we launched a new awareness of an emerging group that previously had no identity, sense of community, or way to organize and advocate for themselves.

Step by step, we taught, supported, informed and advocated to unite individuals and families who live with high risk of hereditary breast and ovarian cancer. Now we are seeing significant return on those efforts, as others recognize our community. More media embrace the previvor movement (see our new online Media page). BRCA articles now appear in national publications. The documentary In the Family poignantly tells our story, as does two books by FORCE members: What We Have (see author Amy Boesky’s story in this issue) and Previvors, the story of five friends who met through FORCE and faced their risk management decisions together. FORCE has a legacy of critically important successes; now we are proud to share another accomplishment on behalf of our community. In September, we made history as the House of Representatives passed H Res 1522, declaring National Hereditary Breast and Ovarian Cancer Week and Previvor Day.

We are no longer without a voice. We are no longer unknown. But we have much left to do, and we intend to continue to be a “force” for positive change on your behalf.

Sue

New Logo, New Look

by Sue Friedman

You’ve been seeing pieces of it: a dual-colored ribbon here and there, more vibrant colors, rumors of something new going on at FORCE, and now our metamorphosis is complete. In September, we launched our new logo and look. We still have deep feelings for the original heart-shaped logo we introduced in 2001. But as awareness about hereditary breast and ovarian cancer grows, we must continue our efforts to reach out to a broader group of people. Our new logo incorporates a fresh twist on the traditional pink-and-teal awareness ribbons. It gives immediate recognition to our mission and makes an instant connection with everyone who sees it.

We’ve also completely redesigned our website. If you haven’t already seen it, we invite you to take a peek. We’ve revamped and reorganized to make the site more appealing and easier to navigate, and we think you’ll agree. It’s the same great resource, whether you want to learn more about HBOC, learn about the latest hereditary cancer research, see what FORCE is up to, take action on advocacy issues, share experiences or ask for support on the very busy message boards. It’s all still there, and now it’s more accessible. The new site also highlights FORCE events taking place all across the country and programs for families who are facing hereditary breast and ovarian cancer. So hop online (www.facingourrisk.org), let your fingers do the work and check out our new look. Come back often…there’s always something new!
Joining FORCES 2011
by Sue Friedman

We are already busily preparing for next year’s Joining FORCES conference:

June 23-25, 2011
Hyatt Regency Grand Cypress
Orlando, Florida

As always, your feedback has been very valuable as we prepare our agenda. Here are some exciting previews:

We are pleased and honored to announce our keynote speaker, Dr. Mary-Claire King. You may know her role in discovering the BRCA1 gene, and you may have seen her in the documentary, In the Family. At Joining FORCES, she will share her unique insights about our community. Don’t miss this!

More opportunities to network. You told us and we listened. Several sessions will facilitate networking by geographic region and by individual circumstances.

Larger Show-and-Tell room. We will expand our popular feature to ensure there is plenty of room for the 200+ expected attendees who come to show, tell, look and learn.

A post-conference pool party. Dip your feet into our gene pool. It was great to let our hair down and party in the pool after this year’s conference. Next year we make it official with a cash bar, and a party atmosphere.

New venue. We are moving Joining FORCES to the Hyatt Regency Grand Cypress, a property featuring 14 lighted tennis courts, 45 holes of Jack Nicklaus golf, an executive pitch-and-put course (free to guests), and childcare (by reservation). Stay tuned to the FORCE website for updates. It is never too early to block your calendar!

Recap: Joining Forces 2010 Conference
by Lisa Rezende, PhD

Dear Talula screening with filmmaker Lori Benson and discussion with Ellen Matloff, CGC

Lori Benson turned her frightening experience with breast cancer into Dear Talula, a hauntingly beautiful film that chronicles a year in her life when she fought breast cancer while transitioning into her role as a mother. The scene that resonated with many viewers shows Benson on her first night home following her mastectomy, holding baby Talula, who desperately wants to breastfeed. The baby is carried away crying, leaving Benson alone. This single moment powerfully illustrates the new reality for many women with breast cancer: while the loss of one’s breasts might seem cosmetic, it represents a very real world where nothing is the same.

Ellen Matloff, a certified genetic counselor, answered difficult questions as the audience reflected on what hereditary cancer means for them and their children. Parents spoke of the difficulty of their children’s unknown genetic status (BRCA testing is only recommended for adults), when they should be tested, and when to reveal their family health history to potential life partners. These issues were particularly relevant for young men in the audience, whether or not they had been tested. Matloff suggested how we can approach these issues with our partners and children, and recommended genetic counseling when appropriate. For those concerned about having children after treatments that cause infertility, she described pre-implantation genetic diagnosis, a technique for women undergoing in vitro fertilization that allows families to screen embryos for BRCA mutations before implantation, assuring that a mutant gene is not passed down to the next generation.

After Surgery, Now What? facilitated by Karen Hurley, Ph.D.

In this informative, interactive session, Dr. Hurley explained that the experience of completing is different for everyone. Beginning with an overview of the transition process based on Transitions: Making Sense of Life’s Changes by William Bridges, she identified three phases: the ending, neutral zone and new beginning. By framing the end of prophylactic surgeries as a process, rather than a single event, many attendees could make sense of their post-surgical feelings and experiences. As Dr. Hurley explained, it is okay to feel relief when surgeries are over, while feeling sad for their result and your loss. She also described the neutral zone, a time after surgery when you are healed, but are still mentally processing the experience. According to Dr. Hurley, many women need to recover first from the physical trauma of surgery and the effects of pain medications before they can approach the mental work needed in the neutral zone.

Diet and Other Lifestyle Factors in Hereditary Breast and Ovarian Cancer, presented by Nagi Kumar, M.D.

Dr. Kumar reviewed evidence linking diet and obesity with cancer, and what individuals with hereditary cancers can do to reduce their risk. Obesity affects cancer risk, but where the body stores fat is also important. People with pear-shaped bodies accumulate most fat in their hips, thighs and buttocks. Apple-shaped body types store fat primarily in the abdomen, which is associated with greater risk of many diseases, including breast cancer. Fat stores and releases some hormones into the body; Kumar suggested this potentially explains why apple-shaped women with BRCA1 mutations have higher breast cancer risk. They should avoid weight gain; losing weight before the age of 30 reduces their cancer risk. Dr. Kumar offered suggestions for reducing the risk of cancer and other chronic diseases:

- Decrease caloric intake by watching portion sizes.
- Improve bone strength with resistance training, and get sufficient quantities of vitamin D.

continued on page 7
Supporting Research through Surveys

by Sue Friedman

The hereditary cancer community is small compared to all people affected by breast and ovarian cancer. When researchers develop new studies, they have important issues to consider, including:

- If we conduct this research will we get enough participants?
- What is the best way to reach participants?
- Will participants be willing to do things we ask of them?
- Do these questions have relevance for the community?

FORCE collaborates with researchers and doctors who are looking for better ways to serve our community. Their research may focus on developing better methods of prevention, detection and treatment, and ways of meeting the support or information needs or improving quality-of-life issues we face as high-risk individuals. Conducting a needs assessment for the target study group is their first step. Learning more about the demographics of their target population helps researchers formulate questions, design protocols, and apply for grant funding to pay for the effort. Competition for limited research funds is fierce; researchers interested in hereditary cancer must be able to show funding agencies that the target population is motivated and willing to participate. Uniting through FORCE and completing our surveys helps FORCE promote research and programs specific to hereditary cancer.

FORCE is conducting surveys to find those who are willing and meet criteria to participate in studies. We are actively seeking respondents for the following two surveys. Visit www.facingourrisk.org/researchsurveys for a complete list of surveys and updates.

Needs Assessment and Research Feasibility for Men with BRCA Mutations

To better understand the needs of high-risk men, FORCE is conducting a survey and developing a contact registry for men with BRCA mutations or their relatives. We encourage individuals who meet the following criteria to complete the survey:

- Men from families with strong history of cancer but no known mutation.
- Men who have tested for a BRCA mutation.
- Men from families that have a known BRCA mutation (whether or not they have had testing).
- Women from families with a BRCA mutation.

Participants who register for the contact registry at the end of the survey will receive updates about new research, information and programs for men with BRCA mutations.

People with Variants of Uncertain Significance (VUS)

Have you received an uncertain BRCA test result, also known as a Variant of Uncertain Significance? If so, we want to hear from you. By completing our survey, you’ll help researchers at the University of Utah advance VUS research and you’ll be entered in our drawing for a chance to win one of three FREE pink iPod Shuffles. If you know someone who has had a VUS result, please share this information with them as well. Visit www.surveymonkey.com/s/uncertainvariant.

All people who are considering genetic testing should see a qualified expert before and after they test. A genetic expert can assure the test is interpreted correctly, and can help people understand their cancer risk based on their family and personal medical history. Women should not make treatment or risk-management decisions based on a VUS test result without input from a genetics expert.

New User Survey for FORCE Visitors

First-time visitors to our website are asked to complete a new user survey to help us shape our programs and better serve our community. Here is what we have learned from almost 26,000 responses over three years.

- About 17% were referred to FORCE from health care providers (60% were referrals from genetic counselors).
- 47% are concerned about their risk for cancer.
- 24% are breast cancer survivors, 4% are ovarian cancer survivors, 4% are survivors of other cancers, and 13% are health care providers.
- 97% are females, 3% are male.
- 88% are Caucasian, 3% African American, 4% Hispanic, 1% Native American and 2% Asian.
- 45% have had genetic testing. Among those, 50% had been recently tested within the year.
- Of the people who had genetic testing:
  - 35% had BRCA1 mutations.
  - 28% had BRCA2 mutations.
  - 4% were “true negative” (tested negative for a known mutation in their family).
  - 8% were uninformative negative (tested negative; no identified mutation in the family).
  - 3% had a variant of uncertain significance.
  - 14% were still waiting for their test results.

FORCE Webinars for High-risk Men

Medical implications of BRCA mutations in men: update and future directions.
Presented by Tuya Pal, MD, FABMG, Moffitt Cancer Center and Research Institute
October 26, 2010
7:00 - 8:00 p.m. EST
Presented by Kelly A. Metcalfe, RN, PhD, University of Toronto
November 18, 2010
7:00 - 8:00 p.m. EST
to register, visit: facingourrisk.org/webinars
Book Review: *What We Have*

by Barbara Pfeiffer

Written with humor and a compelling straightforward style, *What We Have* by Amy Boesky is that rare personal memoir that pulls you in the way only the best novel can. In a story familiar to many of us, the women in Amy's family die too young. Amy, her sisters and their mom live with the threat of ovarian cancer and are urged by their doctors to “start having babies early and get their ovaries out.” So what does a family with three high-achieving (and competitive) sisters do? They plan. But, as the old saying goes, “we plan, God laughs,” and Amy and her sisters find their planned babies and surgery timelines colliding tragically with the unplanned as Amy's sister miscarries. At the same time, their mother develops breast cancer—a big surprise to a family that was expecting ovarian cancer.

In *What We Have*, Boesky tells the story of one year in her family's life; a year filled with wonderful and funny life-changing moments—finding a dream house and having a new baby—as well as life's tragedies: the phone call disclosing her mother's breast cancer. Ultimately, *What We Have* is not about a woman or family facing BRCA; it's about a family with BRCA facing life... all of it. Don't be surprised if you find yourself wanting a sequel. I did.

**Barbara Pfeiffer** is Vice President of FORCE's Board of Directors. Under her direction, FORCE's outreach network has grown from 5 to 60 groups nationwide. She is a partner in Nurture Marketing, a business-to-business marketing agency. Barbara has BRCA1 mutation.

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**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.

**Fighting BRCA with Humor**

by Amy Boesky

Humor is not necessarily the first tool you think of when it comes to dealing with hereditary cancer or making tough choices: Should I be tested for BRCA? Should I have surgery? What kind of tankini am I going to be forced to wear now? Of all the words that start with “h” in our lives—heredity and health chief among them—humor doesn’t necessarily jump to the forefront. But it helps. It's something that has been passed down in my family, from grandmother to mother to daughter. It's something I've inherited that makes me proud.

I come from a BRCA1 family with no history of breast cancer. The mutation showed up as ovarian cancer, claiming my mother's mother at 43, her sister at 45, and her first cousin at 49. My mother had a preventative hysterectomy in her late forties, hoping it would protect her. A few years later, she found a lump in her breast. Tragically, none of us knew then that her cancer was BRCA-related and connected to the cancers that had claimed so many in her family. If my mother's doctors had known, they may have been able to treat her tumor differently. She might still be here, making us laugh. In her absence, part of my mission is to tell her story—our story—with humor as well as with sorrow.

When the going gets tough, the tough... tell a joke. My mother, the queen of wordplay, had a neologism for everything. When she suspected one of us was about to complain we weren't feeling well, she called us “Mellie,” a throwback to Scarlet O'Hara's benighted cousin in *Gone with the Wind*. Razor wit was her best instrument for dealing with anything from an overbearing houseguest to a saccharine-sweet oncology nurse. Humor became the way she reached out to my sisters and me, protecting us from what she couldn't fix. She found a language for telling the world who she was without self-pity.
For me, one of the toughest things about being a previvor has been negotiating the line between keeping all of this to myself and getting out there on the front lines, becoming an advocate. Humor breaks down barriers, and helps to dispel that sense of otherness. It lets me tell my story slant, to borrow Emily Dickinson’s wonderful description. But there's a sly side to humor. Comics from Aristophanes to Augusten Burroughs have always known humor can be an effective tool. If literature holds a mirror up to nature, comedy holds up a distorting mirror. And in that distortion, humor teaches us how to be our best selves—or at least, our better selves.

We need passion, commitment, tenderness and zeal on the front lines of HBOC; a little humor isn’t going to hurt. So, to paraphrase Dickinson: tell the truth. But bend the mirror if you can. It never hurts to laugh, and sometimes it helps more than any of us can guess.

Amy Boesky, Associate Professor of English at Boston College, is author of What We Have, a memoir about her family’s experience with BRCA1.

**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.
FORCE helped make history with our successful efforts to pass H Res 1522, the Congressional resolution declaring the first-ever National Hereditary Breast and Ovarian Cancer Week (9/26-10/2/2010) and National Previvor Day (9/29/2010). In support of this effort, we are launching our first “Raise Your Voice” awareness campaign for hereditary breast and ovarian cancer.

This campaign recognizes everyone affected by hereditary breast and ovarian cancer syndrome, including women and men with BRCA mutations, people with a family history of cancer, and breast and ovarian cancer survivors and previvors who have faced hereditary cancers. A lot of misinformation still exists about hereditary cancer and most people with inherited mutations are unaware of their risk. We need funding allocated specifically for hereditary cancer; it represents about 10% of all breast and ovarian cancers and deserves a proportionate share of the research budget.

We believe the resolution and our campaign will save lives! You can help make a difference. Join us in this campaign over the next several weeks and make your voice heard by:

- Ordering FORCE brochures from our website and providing them to your medical team.
- Sharing your voice and posting your story online at FORCE.
- Donating to FORCE and helping us continue the fight against hereditary breast and ovarian cancer.
- “Liking us” on Facebook.
- Proudly wearing FORCE logo items, talking with others about HBOC, and shining a spotlight on hereditary cancer.

When you became a FORCE member, you took an important step to becoming more educated, informed and empowered: qualities you’ll want to instill in your children when the time is right. But you can empower them now and make it fun, with fundraising for FORCE—it can help your children feel involved, and provide them with a sense of control over something that may have previously evoked only helplessness and fear. It’s also a great way to reinforce the importance of helping others. Kids are capable! Just look how some are making a difference:

In 2008, Emma (age 14) and Sofie (age 17) Seymour, along with Jackson and Emily Red of Narberth, PA, sold lemonade to increase awareness of hereditary cancer. They took in $800 their first summer, and $2,000 the next with a matching corporate donation. Their roadside stand has grown into G’s Lemonade, a charitable organization. This summer, they’ve been out in “force” and plan to provide a generous donation this fall. Thank you, girls!

Nine-year-old Emmie Cohen of Lafayette Hill, PA, organized a community service fundraiser for FORCE in conjunction with the Girls on the Run 5k race. Her teammates made donations in exchange for FORCE race bibs, which they wore during the run to honor the memory of loved ones and friends. Emmie and her pals raised more than $1,000 with a matching corporate donation. Great job, Emmie!

During Breast Cancer Awareness Month, Gillian Dysart, 10, of Yardley, PA, sold adorable shirts and totes from FORCE partner Tiny Little T-Shirt Co™ simply by e-mailing notes with a link to the company’s website. Gillian raised over $3,000, and thanks to her, FORCE received more than half the amount.

Inspire your children and encourage their ideas. See what their fertile minds come up with or contact sandrac@facingourrisk.org for ideas.

Amy and Jody are FORCE members in Philadelphia.
Update: WISER Sister Study
by Kathryn Schmitz, Ph.D., M.P.H.

Women in the Steady Exercise Research (WISER) Sister study will help researchers determine how exercise affects breast cancer risk. With the help of our partnership with FORCE, we are halfway to our recruitment goal of 160 high-risk women. Participants will be categorized into one of three exercise groups, which will determine their exercise program over the eight-month course of the study. We anticipate that recruitment will continue for at least another year (through summer 2011), so please refer any family members who will be age 18 or older in the coming year!

We have been so moved by the many stories shared with us by our participants. They have experienced relatives being diagnosed with recurrent breast cancer, as well as family deaths, divorces, moves, job changes and major medical events. All they share with us puts into sharp focus that being at high risk for cancer occurs in the context of the usual busy lives of women. And yet, they find time to provide urine samples, travel to Philadelphia and exercise! Our participants are our heroes! Here are comments from a few of them:

“My WISER Sister journey has been one of personal growth and positive change…”

“Participating in the Wiser Sister study has been a worthwhile experience. I became more physically fit, while helping researchers discover whether exercise decreases breast and ovarian cancer risk. I was randomly selected to do 300 minutes of cardio per week. It seemed daunting in the beginning, but I was excited about adding exercise into my daily routine and getting back into shape. Having someone monitor my progress was great motivation to change my sedentary lifestyle. As soon as my free treadmill was delivered, I began with 150 minutes of cardio vascular activity. By the third week, I was in a routine, and I looked forward to my daily treadmill appointments. Over 11 weeks I gradually increased to 300 minutes per week. Cardio is now a part of my daily routine. I feel and look better, but most importantly, I like knowing that I’m doing something to possibly reduce my cancer risk.”

“I am 33 and the mother of two young boys. My mom, aunt and grandmother had breast cancer. I want to do everything I can to avoid it; one way is participating in this research. My resolution this year is to finish this project and run one 5k race a month. I ran one in January, and this weekend I will run my second. Before this study, I was the girl who did not exercise at all.”

“Participating in the WISER sister study has been a profoundly positive and personal experience. With my friends and family who have participated, I share a special bond of having gone through a life-changing and habit-changing experience together. As women at high risk for breast cancer, we have all committed to be a part of the study to take positive action for ourselves and other women. The team at the University of Pennsylvania was incredibly supportive, encouraging, flexible and patient. My WISER Sister journey has been one of personal growth and positive change as I learned to make time to exercise and do the things needed to promote my continued good health.”

Kathryn Schmitz, PhD is an Associate Professor of Epidemiology at the University Of Pennsylvania School of Medicine.

Diet and Other Lifestyle Factors continued

- Prevent muscle loss through physical activity, resistance training and consumption of high-quality proteins.
- Eat at least 8-10 fruits and vegetables a day.
- Get the recommended 20-30 grams of fiber per day by eating whole grains.
- Take a USP-verified multivitamin supplement that does not contain mega doses of vitamins (not more than 10 times the RDA).
- Use monounsaturated fats, such as olive oil or canola oil.
- Stop smoking and avoid exposure to second-hand smoke.
- Avoid sun exposure by using sunscreen with an SPF of 15 or higher. Wear hats and other protective clothing, and don’t use tanning beds.

Lisa Rezende, PhD is a previvor and lecturer in Chemistry and Biochemistry at the University of Arizona.

To be eligible for WISER Sister Study, you must:

- Be age 18-40.
- Have elevated risk for breast cancer due to family history, but not diagnosed with breast cancer yourself. You do not need to be tested for a BRCA mutation to participate.
- Be willing to refrain from taking any hormonal medications during the study, including tamoxifen and hormonal contraceptives.
- Live anywhere in the United States to participate, but be willing to travel to Philadelphia twice: once in the first of seven menstrual cycles during participation, and once in the last (7th) menstrual cycle during participation. Travel expenses will be reimbursed if you live more than 75 miles away.
- Be considered sedentary—you have no more than an hour of vigorous physical activity per week. The study staff will help you determine if you are too active to participate.

For more information or to participate, visit [http://bmic.upenn.edu/wiser](http://bmic.upenn.edu/wiser) or join the WISER Sister Study group on Facebook. You can also contact us at wiser@mail.med.upenn.edu.
What’s New @ FORCE

Life. Be Empowered
The FORCE-exclusive tee from Tiny Little T-Shirt Co.™ is here! Celebrate life and support FORCE with our new “Life. Be Empowered” tee. Check out this design and all the other uplifting, fun and inspirational apparel and beach totes from a company that generously gives to our organization every time you make a purchase. Enter the “FORCE” promotion code at checkout, and we will receive 25% of your total purchase. We also receive $5 for every “Be the cure,” “Be empowered” and “Peace, Love, Hope” pink ribbons designs, so stock up. The holidays are quickly approaching and they make great stocking stuffers! Visit: www.facingourrisk.org/partnershop to order your tshirt.

Passing of the Torch from Ovarian Cancer Awareness Month to Breast Cancer Awareness Month®
FORCE and Kaleidoscope of Hope Foundation present “Passing of the Torch” to highlight the hereditary link between breast and ovarian cancer, honor cancer survivors and those at high risk, remember those whose lives have been lost to cancer, and recognize families that have been affected by cancer. This year our organizations will hold four Passing of the Torch events:
• September 30 Passing of the Torch in Cincinnati at the Reds’ home game.
• October 1 Passing of the Torch in Morristown, New Jersey at the College of Saint Elizabeth.
• October 29 Passing of the Torch in Washington D.C. at the Nationals’ home game.
• View our virtual Passing of the Torch Park on the FORCE website. Visit: facingourrisk.org/passingofthetorch for more information.

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.

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.