Patients Power the ABOUT Network
by Lisa Rezende, PhD

The ABOUT network is the first research registry developed by and for the hereditary cancer community. You decide how much or little you wish to be involved, and choose how to become involved:

1. Enroll in the registry: Enrollment can be done online in about 20 minutes at aboutnetwork.org. Once registered, you will receive quarterly updates and notification of research studies that might interest you.

2. Take an engagement survey: Using informal engagement surveys, ABOUT “takes the pulse” of the hereditary cancer community and helps to formulate questions for formal research studies. Our current survey asks about your experiences sharing cancer risk information with adult family members. Past surveys collected women’s experiences facing risk-reducing removal of ovaries and fallopian tubes, mastectomy, and surgical menopause.

3. Free your data: On our website, www.freethedata.us, you can anonymously contribute your mutation data to Clinvar, a public database of genetic mutations.

4. Spread the word: Patients need to be involved in research; share the value of ABOUT with your blood relatives and friends who are affected by hereditary breast and/or ovarian cancer.

Patients make up the majority of governance of the ABOUT network; volunteer patient advocates sit on the steering committee and all work groups. Graduates of the FORCE Research Advocate Training program are also invited to apply to ABOUT. For more information, visit http://www.facingourrisk.org/our-role-and-impact/advocacy/research-advocate-program.php.

9th Annual FORCE Conference Opens with Self Empowerment, Call to Action
by Katrina Altersitz Wells

The opening session of our 2015 Joining FORCEs Against Hereditary Cancer conference welcomed attendees with words of self empowerment and a renewed call to action.

Clinical psychologist Karen Hurley, PhD, explained how instinct can bring a sense of forward motion. “It's not a small thing to trust our instinct when we feel like our bodies…have betrayed us,” Hurley said. “But we can use the science to create a sense of wholeness…in building an alliance.”

She cautioned attendees to not neglect their basic needs when becoming engulfed in overwhelming amounts of conference information, saying that food and sleep are of utmost importance, as are connections with other attendees. “Sometimes it feels like DNA holds the power, but our real power is in how we live our lives, given what life puts in front of us, what dreams we dream, what goals we achieve, who we love and how,” Hurley said. “We live empowerment in our decisions and through our connections. We have come together today, this weekend, to make empowerment a reality.”

Barbara Pfeiffer, CEO of FORCE, then called upon attendees to never lose vigilance. Fights that have been won—such as the implementation of GINA—are being challenged, and the HBOC community cannot afford to stay quiet. “We won that battle. We shouldn't be going back again,” Pfeiffer said. “If we take our eyes off…if we don't make noise, they're not going to hear us.”

Continuously fighting for what is needed will maintain the momentum to change the world for the children of the HBOC community, Pfeiffer explained. “It should not be the same 10 years from now as it was 10 years ago. We need better choices than cutting off body parts. We need to keep this going.

Katrina is a BRCA1 carrier living in South Jersey with her husband and daughters. She works in medical publishing, and is using data and family history to navigate her journey.
Joining FORCEs Conference Returns to Orlando: October 6-8, 2016

by Lisa Rezende, PhD

The Joining FORCEs conference is the largest conference organized by and for the hereditary breast and ovarian cancer community. Join us for our 10th conference, October 6-8, 2016, at the Hyatt Regency Grand Cypress hotel in Orlando, Florida.

Conference Recap: When is Hormone Replacement Appropriate in Women at High Risk for Cancer?

by Katrina Altersitz Wells

A question that is on the minds of almost every woman in the HBOC community as they weigh their ovarian cancer risk is the side effects of early menopause after oophorectomy, closely followed by the question of hormone replacement therapy (HRT) and its safety.

Andrew M. Kaunitz, MD, FACOG, NCMP, and Noah D. Kauff, MD, FACOG, took on the heavy burden of weighing the pros and cons of HRT for attendees at the 9th annual Joining FORCEs Against Hereditary Cancer conference. Both agreed that the biggest factor in treatment of postsurgical women, even those at high risk, is how they react to the surgery and how they feel. “It’s not for me to decide. It’s for my patient to decide,” Kaunitz said.

Kauff noted that much discussed factors, like protection from cardiovascular disease, may be less important than previously thought. He pointed out that HRT is not recommended for prevention of heart disease or improvement of cognitive function in the general population, so perhaps it should not be considered as such in the HBOC population. Instead, it should be used exclusively for the treatment of vasomotor symptoms of menopause (influences that cause blood vessels to constrict or dilate). “I’m not convinced [oophorectomy] increases heart disease at all. We should not be taking HRT to protect against a risk that may not be real,” Kauff said. “I suggest they wait for symptoms to declare 3-4 weeks after surgery.”

Kauff admitted that he may be more conservative than others, and if a prophylactic mastectomy has not been performed, there is much more to consider. “One group of women to whom I empirically offer HRT are those that already had prophylactic bilateral mastectomy,” he said. “If breast cancer risk is off the table due to mastectomy, it’s reasonable to give hormone therapy until the age of natural menopause.”

But Kaunitz presented data from three studies of HBOC women with intact breasts who took hormone therapy, which he felt shows this population can safely take HRT up to 5 years. One study (Rebbeck, et al., 2005) showed that risk-reducing oophorectomy further decreased the risk of breast cancer by 60% whether or not women used HRT; 2-3 years of HRT did not negate the beneficial effect of oophorectomy. Another study (Eisen, et al., 2008) “counterintuitively” found greater than a 40% reduction in breast cancer with hormone therapy. Yet another study (Domchek, et al., 2011) showed that HRT was not associated with increased risk of breast cancer, and in BRCA1 carriers, use of hormone therapy was again associated with a decreased risk of breast cancer, regardless of previous gynecologic surgery.

“Up to 5 years of HRT use appears safe. Specifically in BRCA1 previvors, hormone therapy appears to reduce the risk of breast cancer,” Kaunitz said. “Previvors with intact breasts should not defer risk-reducing gynecologic surgery out of fear of symptoms related to surgical menopause.”

Additionally, Kaunitz warned attendees against the use of unapproved hormonal options like compounded formulations or bioidentical hormones. Many physicians who prescribe and self compounded hormone therapy also often charge for testing, he explained. While lucrative for prescribing physicians, the salivary tests taken to monitor the presence of compounded hormones do not correlate with blood levels.

Kaunitz encouraged attendees to find an educated physician for the menopausal journey. “It is worth the effort to seek out well informed, up-to-date clinicians who involve their patients in choices regarding menopausal management,” he said.

Kauff agreed, bringing it back to the real risks of ovarian cancer that women under the HBOC umbrella must weigh. “We do not have an adequate ovarian cancer screening. Our only option...is removal,” he said. “Salpingo-oophorectomy is when, not if, but we always have to remember we’re dealing with two cancers. We shouldn’t necessarily just prescribe hormone therapy without an indication. Treat it like any other drug where there are benefits and downsides.”

The conference offers the opportunity to hear from leading hereditary cancer experts. You will learn the latest on cancer risk management, hereditary treatment, breast reconstruction, menopause management, and communicating risk with children and adult family members. Informative sessions will be available for people at all stages of their HBOC journey; those who recently tested will find the latest information risk-management options, cancer survivors will learn about new treatments and clinical trials targeting hereditary cancer, and longtime FORCE conference veterans will learn about the latest advocacy issues and find ways to give back to the community. Everyone will benefit from the sense of community that comes from networking with other people who truly understand what it is like to face a personal risk of cancer everyday.

While the daytime conference agenda is filled with information, evenings will feature our popular after-hours events, including the “Show and Tell” room where women share their mastectomy stories and results with women who are considering mastectomy. Other events will be posted on our conference site (www.facingourrisk.org/get-involved/events/annual-conference/index.php).

Save the date and join us in Orlando in October!
Conference Recap: Forum on Population Testing for BRCA

by Julie Huynh

“To identify a woman as a carrier only after she develops cancer is a failure of cancer prevention,” says Dr. Mary-Claire King in her 2014 viewpoint article in The Journal of the American Medical Association.

As genetic testing becomes more affordable and available, the possibility of testing all women for BRCA mutations, often called population testing, becomes more feasible. Often, women with BRCA mutations only become aware of their mutation after they have been diagnosed with cancer—either because their family cancer history was not known or recognized for a number of reasons, including small family size or inheriting the mutation from their father. While mutations in BRCA predispose carriers to high breast and ovarian cancer risks, knowing that you have a BRCA mutation provides access to many treatment and preventive options. However, while population testing would help identify women without a strong family history of breast cancer, costs also need to be considered.

To better understand the issues, FORCE convened a panel of experts at the 2015 Joining FORCEs closing session, including Anya Prince and Drs. Tuya Pal, Susan Vadaparampil, Timothy Rebbeck, and Olufunmilayo Olopade, to discuss the issue of BRCA population genetics and population testing.

Dr. Rebbeck discussed factors that must be considered when discussing population testing for BRCA. He outlined criteria for population testing for a disease and explained how BRCA population testing fits into these criteria:

1) Is it an important public health problem for other populations?
   a. Yes, 1 in 400 people who are not of Ashkenazi Jewish decent will have a mutation.

2) Do mutations confer high risk?
   a. Yes, for BRCA1 mutation carriers, the risk of developing breast cancer is approximately 46-59%, while the ovarian cancer risk is approximately 33-36%.

3) Do effective interventions exist?
   a. Yes, proven preventive measures (e.g., breast screening, prophylactic breast and ovarian surgery) are available for people with BRCA mutations.

These criteria indicate that BRCA population testing is something worth considering. But, Dr. Rebbeck emphasized that related costs and benefits should also be examined. While the risk of developing breast cancer is high in mutation carriers, it is not 100%, meaning that not all women with BRCA mutations will develop breast or ovarian cancer. Unnecessary interventions may occur—if the risk is not 100%, someone will get tested, and someone will have an oophorectomy that was unnecessary because she would never develop ovarian cancer. From a public health perspective, the cost of testing, medical and psychosocial harm, and the potential to incur unnecessary interventions need to be weighed against the breast cancers prevented, especially in non-Ashkenazi Jewish populations.

Anya Prince talked about population testing from a policy perspective, focusing on how it could be implemented. She is working on the GeneScreen research project to determine whether a public health program screening asymptomatic adults for rare and medically actionable mutations is feasible, ethical, and socially sound. She raised a number of questions that must be considered before population testing can be implemented, including:

- how are findings communicated to individuals?
- where does the screening occur? Does it involve a genetic counselor or not?
- how is clinical follow-up of mutation carriers managed?
- who pays for testing, both from a societal and individual perspective?

The closing session ended with Drs. Tuya Pal and Susan Vadaparampil presenting the pros and cons of BRCA population testing.

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The compiled resources on our “Should I Get Testing?” page are for anyone who is concerned about hereditary cancer in their family, and includes:

- signs of hereditary breast and ovarian cancer.
- a chart to record your family history.
- a table of genes that are linked to hereditary breast and ovarian cancer.
- information on how to find a genetics expert in your area.
- resources on paying for genetic testing.
- information about insurance.
- a list of labs that offer testing.
- information regarding where you can find support during the genetic testing process and after you receive your results.

Please share this valuable resource with friends and family members who might be at risk for hereditary cancer. Go to www.facingourrisk.org/shouldigttested.

### Reaching Out to Family Members

**Lara Diamond**

After inadvertently testing positive for a BRCA2 mutation, my life was thrown into turmoil. At first, I wished I didn’t have this information, when I grasped what it meant for my immediate family. I was able to reach out to my immediate family, but I was able to reach out to more distant cousins as well to let them know of this mutation in the family.

One branch of the family already knew they had a mutation, discovered after a cousin’s ovarian cancer diagnosis. However, they hadn’t reached out to my part of the family, since we were descended from a different wife. I explained how mutations are just as likely to come from men as women, a fact that too few understand.

I was able to tell my cousins how the knowledge of my having this mutation caught my cancer at a much earlier stage than it would have been otherwise. My real-life stories were one of the reasons of my knowledge led dozens of my relatives to test; in fact, my genetic counselor (whose name I had given everyone) asked me what I said to have so many people call her within a week for an appointment. Many relatives did test positive and can now be proactive with their health.

**Lara Diamond is a BRCA2 mutation carrier, a mathematician and a genealogist.**

### Beyond BRCA: Testing for Mutations in Other Genes that Increase Cancer Risk

**Sue Baker**

In August of 2015 I was diagnosed with stage 1 breast cancer; further tests revealed that I have a mutation in the BRIP1 gene. Because my health provider has only been testing for BRIP1 mutations for the past year or so, I consider myself lucky to have been able to be tested. It is sobering to think that if I’d been diagnosed with breast cancer even a year ago I might not have been tested for this mutation, and would have missed getting important information about further care that might well save my life.

The BRIP1 mutation is a “moderate risk” mutation, and is connected to a higher incidence of breast cancer and ovarian cancer. While research on this gene is in the beginning stages, studies suggest that the risk of breast cancer in BRIP1-positive women is 22-33%, and the risk of ovarian cancer is 5-7%. Currently, there are several recommended courses of action, including heightened monitoring and prophylactic surgery.

Because I am BRIP1 positive, have a family history of premenopausal breast cancer (my mother at age 38), a history of melanoma, and had stage 1 breast cancer, my doctors recommended a bilateral mastectomy and an oophorectomy with removal of the fallopian tubes. I underwent the mastectomy in September and will have the hysterectomy in the spring. I’ve elected to have a full hysterectomy because I would rather have my uterus and cervix removed to eliminate any chance of cancer in those organs—it is a personal choice.

While my positive diagnosis of the BRIP1 genetic mutation was a shock, I am grateful for the information (knowledge is power, right?), and also for the opportunity to have prophylactic surgery. Not to be Pollyanna-ish, though, this entire thing has been a difficult journey that I would have much rather avoided.

For more information on the BRIP1 genetic mutation visit http://www.facingourrisk.org/understanding-brip-and-brcas-information/hereditary-cancer-in-other-genes/basic-brip1.html

**Sue Baker is the mother of a 14-year-old son, and is a Professor in the Department of Teacher Credentialing in the College of Education at CSU Sacramento.**

### 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.
They apply established criteria for population screening to the proposal to test all women at age 30, regardless of family history.

BRCA population testing offers many advantages. Breast cancer is an important public health problem, and the high breast cancer risk for BRCA mutation carriers is known. However, most studies have been done in people with known family histories of breast cancer; whether the level of risk in the general population will be the same is unknown. Will the risk for breast cancer be as high for people with a BRCA mutation but no family history of breast cancer as it is for those with a family history?

In terms of BRCA testing itself, population testing would potentially increase access to testing, and thus screening and risk-reducing measures. However, it is not known if all women will accept genetic testing. The role of pre-test genetic counseling and informed consent before testing must be explored on a population basis.

Regarding the pros and cons of population testing, when talking about risk management for BRCA mutation carriers, a pro is that guidelines for managing breast and ovarian cancer risk are already established. However, while they effectively prevent breast and ovarian cancer, it is unclear if these risk management options will be acceptable to all populations.

Finally, Drs. Pal and Vadaparampil considered the cost of testing to the health care system as a whole. Research shows that population-based BRCA testing is cost effective in the Ashkenazi Jewish population where BRCA mutations are more prevalent. The cost in a more diverse population is not yet established. They concluded that population testing holds the potential for identifying more BRCA mutation carriers, and would remove known barriers to testing in the United States. However, more research needs to be done on the risk of cancer in people with BRCA mutations and no family history. In addition, the role of genetic counseling and assuring all patients have proper informed consent before testing must be addressed.

Dr. Olufunmilayo Olopade closed the forum with a call to action. She said that people can argue about testing penetrance. We know that everyone with a mutation is not going to get cancer. Individuals with mutations have different ways to manage their risk: some want only screening, while others want surgery. People are unique, but we need to give them the chance to make their own decisions about what they want. We should not be paternalistic and say that people will not know how to handle it.

“The time is now,” Dr. Olopade said. “We have more work to do—the work is not done.”

Dr. Olopade finished by saying: “I think what we need to do is think about prevention and early detection, and we’re not going to get it by doing business as usual.”
Conference Recap: Preventing and Treating Cancers in High-risk Men
by Melissa Cranmer

While much is known about managing cancer risk in women with mutations in BRCA and other genes associated with hereditary breast and ovarian cancer, less research focuses on men with mutations. At the 2015 Joining FORCES conference, Dr. Mary Daly of Fox Chase Cancer Center presented what is known and what research is needed.

In the average-risk population, cancer incidence and mortality is actually greater for males than for females. Several cancers disproportionately affect males. Globally, colorectal cancer rates are higher in men than women, as are lung cancer and bladder cancer. While some of this seems to correlate with increased exposures to certain pathogens, such as smoking and other factors that cause lung and bladder cancer, it is unclear to what extent exposure influences risk. Multiple factors are believed to play a role in cancer risk, including:

- lifestyle factors: diet, exercise, tobacco/alcohol use, screening behaviors.
- environmental factors: occupational exposures, medications, pollution, infectious diseases.
- individual biological makeup: age, race/ethnicity, immunity, body mass.
- genetics: acquired genetic alterations, congenital conditions, inherited genetic alterations (BRCA, Lynch syndrome, etc.).

How these factors interact and affect one another is poorly understood.

Men who test positive for a genetic mutation exhibit better cancer screening, surveillance, and health habits, which generally have a positive effect on health. Men with children are more likely to be tested for a genetic mutation than those without children, due to their inclination to protect their children (as opposed to protecting themselves). Overall, fewer screening, treatment, and prevention options are available for men with genetic mutations.

BRCA mutations increase the risk of two forms of male cancers: male breast cancer and prostate cancer. Male breast cancer accounts for less than 1% of all breast cancers, however men with a BRCA2 mutation carry a 7% lifetime risk of this type of cancer. Screening for male breast cancer is challenging, as many men lack enough breast tissue to adequately perform a mammogram. Male breast cancers with a palpable mass tend to present at later stages, and no current research exists on effectiveness of ultrasound in men. Treatment of male breast cancers also has unique challenges: no clear guidelines have been developed as to whether or not lumpectomy or mastectomy is best, nor whether lateral or bilateral mastectomy should be performed. In addition, some treatments (such as tamoxifen in ER-positive breast cancer) have undesirable side effects (such as impotence) and may compromise compliance with treatment regimes.

Prostate cancer risk is also increased in men with BRCA mutations, with BRCA1 mutations carrying a 3-fold risk and BRCA2 mutations carrying a 7-fold risk. BRCA mutations are also associated with younger age at initial diagnosis, more aggressive cancers, and higher rates of nodal and distal metastases. Men with BRCA mutations also have a higher rate of recurrence and mortality. Questions on how to best treat and screen BRCA-related prostate cancer (radical vs. local therapy, active surveillance, targeted chemotherapy, PARP inhibitors) remain; however, prostate screening at a younger age (40 years) should be considered.

Colorectal cancer also carries a strong hereditary factor based on multiple mutations and syndromes, including familial adenomatous polyposis, MYH-associated polyposis, Lynch syndrome, familial colorectal and pancreatic cancers, inflammatory bowel disease, Peutz-Jeghers syndrome, and juvenile polyposis. Lynch syndrome not only causes a marked increase in colorectal cancer, but also increases the risk of other cancers as well, including cancers of the brain, urinary tract, pancreas, and small bowel.

Lack of research, public misconceptions about how inheritance affects risk, and a lack of involvement with a family health care delivery system presents additional challenges to effectively screen, prevent, and treat cancer in high-risk men.

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New Film Suggests the Breast Cancer Ribbon Should be Pink…and Blue
by Sandra Cohen

Breast cancer is not only a woman’s disease. It affects men as well, especially men who have a genetic mutation in the BRCA1 or 2 genes. FORCES is excited that Pink & Blue, the new documentary directed by Alan Blassberg and produced by Amy Shainman, helps to educate and raise awareness about BRCA mutations and male breast cancer. Media coverage of the mutation is increasing, but not so much on how it affects men. Pink & Blue changes this by sharing inspirational stories of men, women and families affected by hereditary breast and ovarian cancer, along with facts from renowned doctors in the field.

In the film, Blassberg shares his sister’s journey with breast cancer, and his own navigation through screenings and discussions about his risk. He highlights how the screening process needs to adapt to accept men as patients into the breast cancer world, and to help men cope with this disease in a more masculine way. Men are already uncomfortable talking about breast cancer, and there’s a real need to make a change. Blassberg is hoping to start that conversation with this film and include blue into the breast cancer equation.

Fun fact: The Pink & Blue team filmed at our 2014 Joining FORCES Conference, and many FORCES members can be spotted throughout the documentary. The film also features stories about two of our volunteers: Detroit Peer Support Group Leader, Marla Ruhana, and our Michigan Community Liaison, Molly Smith.

Stay tuned to learn when the film is coming to a screen near you.
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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 newsletter@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.

Conference Recap: Preventing and Treating Cancers in High-risk Men  continued

The future of high-risk cancer screening and prevention may take several forms, including multiple-gene panel testing, whole genome sequencing, and universal genetic testing.

Melissa found FORCE while searching for an internship project as part of her public health degree. Having lost both her mom and maternal grandmother to breast cancer, she strongly connects with FORCE’s mission. She also has a master of business administration, and hopes to use her educational background to further public health initiatives, especially in the field of women’s health.

What’s New @ FORCE

FORCE is continually adding new expert-reviewed content to our website. Check out the FORCE website for new and updated content on:

- treatment for breast and ovarian cancer.
- genes (other than BRCA) that increase cancer risk.
- quick references to national guidelines on genetic testing and managing cancer risk.
- paying for care.
- managing menopause.
- risk and screening for pancreatic cancer and melanoma.

More updates are planned for 2016, so keep checking with FORCE for the latest high-quality information on hereditary breast, ovarian, and related cancers.