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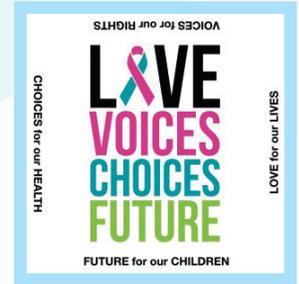
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For Our Children

by Sue Friedman, DVM

For 16 years FORCE has been there for you. Now we are calling on our community to make sure that FORCE is here for the next generations. The "For Our Children Campaign" will strengthen FORCE so that we will continue to fight in the years to come for better awareness, treatment, prevention, and care for hereditary cancers. Every dollar raised by this campaign will go towards FORCE research, support, education, and advocacy efforts. Visit facingourrisk.org/forourchildren to create a personal page and help us to create a future where hereditary cancer is no longer a threat.



Update from the ABOUT Patient-Powered Research Network

by Sue Friedman, DVM

The ABOUT Network is the first research registry created by and for people affected by hereditary breast, ovarian, and related cancers (HBOC). Members of the HBOC community set the direction of the research.

Who can join the ABOUT Registry?

Anyone with a personal or family history consistent with HBOC can join, including:

- people with a personal/family history of breast, ovarian, prostate, melanoma or pancreatic cancers, whether or not they have had genetic testing
- all ovarian cancer survivors
- all breast cancer survivors with triple-negative breast cancer
- all breast cancer survivors diagnosed at age 50 or younger
- all men and women with a BRCA mutation and their adult blood relatives (whether or not they have had cancer or genetic testing)
- anyone whose family has a mutation in other genes that increase risk for breast, ovarian, prostate, melanoma or pancreatic cancers (for example, PTEN, PALB2, etc.)

Enrollment

ABOUT has enrolled over 5,800 people into the research registry, almost one half of the way to our goal of 12,000. If you have not yet enrolled, it's easy to help advance research by visiting our public portal at aboutnetwork.org, signing the consent, then filling out a 15-minute baseline health questionnaire.

Periodically we will ask you to fill out surveys and

updates on your health and medical decisions, and we will alert you about clinical trials for which you qualify.

Governance

The ABOUT Network research, communications, enrollment, and dissemination are overseen by members of the community who participate on our Work Groups and Steering Committee. If you are interested in participating in network governance, you can apply by visiting the Research Advocate page on the FORCE website at facingourrisk.org/advocate.

Research

Our research goal is to learn which medical decisions lead to the best health outcomes for patients. Engagement surveys are one of the tools that help us to understand how people make medical decisions about hereditary cancer, and identify key areas where more research is needed to help consumers make informed decisions.

Our first engagement survey queried high-risk women about factors that influenced their decisions involving hysterectomy (surgical removal of the uterus) during risk-reducing removal of ovaries and fallopian tubes. About half (49.5%) of women surveyed removed their uterus and half (50.5%) kept theirs. Factors that influenced these decisions included:

- concern about uterine cancer risk
- doctor's recommendation
- history of prior uterine abnormalities (such as fibroids)

continued on page 3

Are You Willing to Spit for Science?

by Pamela Kline

Join the Basser Research Center for BRCA's Research Registry at Joining FORCEs 2015

The Basser Research Center for BRCA invites you to consider participating in their research registry, Identification and Analysis of Families with Genetic Susceptibility to Cancer. Participation involves providing your personal and family history, a saliva sample and key medical records. At the conference, stop by the Basser table to see if you are eligible. Enrollees will receive a t-shirt from the Basser Center.

If you are a BRCA mutation carrier (or mutation carrier of another cancer risk gene) and interested in participating in research, PLEASE BRING A COPY OF YOUR GENETIC TEST RESULTS TO THE CONFERENCE.



Update from the Basser Research Center for BRCA

by Pamela Kline

The Basser Research Center for BRCA is pleased to partner with FORCE. Our collaboration strengthens ties between people coping with BRCA-related issues and the researchers and physicians devoted to finding new ways to prevent and treat BRCA-related cancers. "Individuals involved with FORCE can play a key role in helping us shape our research agenda by telling us about their experiences and helping us understand what information and resources are important to them as they navigate the process of receiving genetic test results, planning strategies to reduce their risk of developing cancer, or receiving treatment for the diseases linked to these genes," says Susan Domchek, MD, Executive Director of the Basser Research Center for BRCA.

FORCE and the Basser Center work together to develop educational resources, drive research forward, and ensure that support resources are available to individuals facing hereditary breast and ovarian cancer.

- FORCE served as a collaborator on the Basser-sponsored poster campaign to

raise awareness about BRCA in the Jewish community. This campaign provided posters to 1,500 synagogues across the country.

- Basser served as a partner for the 2014 Joining FORCEs conference, which was attended by more than 700 individuals facing hereditary breast and ovarian cancer. Nearly 300 individuals enrolled in Basser-sponsored research projects during the conference.
- Basser is proud to be a returning partner for the 2015 Joining FORCEs conference. Basser continues to refer patients to FORCE's key support resources, including its local support groups and national helpline.

For more information about the Basser Research Center for BRCA, visit www.basser.org. Follow Basser on Facebook at www.facebook.com/BasserBRCA.

Pamela Kline is the Outreach Coordinator for the Basser Research Center for BRCA

Penn Study Shows Risk of Breast and Ovarian Cancer May Differ by Type of BRCA 1/2 Mutations

In a study involving more than 31,000 women with cancer-causing mutations in the BRCA1 or BRCA2 genes, researchers at the Basser Research Center for BRCA, the

"...the risks of breast or ovarian cancer are different depending on the location of the mutation within the gene."

Abramson Cancer Center, and the Perelman School of Medicine at the University of Pennsylvania demonstrated that the risks of breast or ovarian cancer are different depending on the location of the mutation within the gene. Authors say the results show that some mutations in some areas confer

higher risks of breast cancer relative to other mutations, while mutations in other areas show relatively higher risks of ovarian cancer. These findings may lead to more effective cancer risk assessment, care and prevention strategies. Additional research is required to determine what level of absolute risk change between mutation types will influence medical decision making and standards of care, such as timing of preventive surgery, for carriers of BRCA1/2 mutations.

Reference:

Rebbeck TR, Mitra N, Wan F, et al. "Association of Type and Location of BRCA1 and BRCA2 Mutations with Risk of Breast and Ovarian Cancer." *Journal of the American Medical Association* (2015) Vol. 313, No. 13, pp. 1347-61.

9th Annual Joining FORCES Conference

by Sue Friedman, DVM

On June 18-20 people from all over the globe will converge in Philadelphia for our 9th annual Joining FORCES conference. This highly anticipated gathering brings together survivors, previvors, world experts, researchers, biotech companies, and advocates to share experiences, resources, and knowledge on HBOC.

Sessions for Every Situation

No matter what your situation—whether you are a survivor or previvor, male or female, newly-diagnosed or in treatment or post-treatment, if you've had surgery or you are undergoing enhanced screening, whether you have made all of your health care decisions or are in the process of trying to choose, our sessions will help you on your HBOC journey:

- More than 10 breast, reconstruction, gynecologic, and lymphedema surgeons will speak about risk-reducing surgery, managing surgical complications, breast reconstruction, and making surgical decisions.
- Genetics experts will demystify different genetics tests
- Experts will discuss the effects of menopause and hormonal and nonhormonal options for managing symptoms.
- Specialists will speak about strategies to reduce risk and improve quality of life using diet, exercise, and complementary medicine.
- Physicians will discuss fertility preservation and treatment, preimplantation genetic diagnosis, and other parenting options for survivors and previvors.
- Researchers will present the newest treatment options, including updates on PARP inhibitors and targeted therapies being researched for HBOC.
- Experts will advise how to understand research reports, navigate insurance, identify your legal rights, and how to help shape the future of HBOC research.
- Networking, panel discussions and workshops will allow you to meet, learn from and share your story with peers, and speak face-to-face with experts.

ABOUT Patient-Powered Research Network *continued*

by Sue Friedman

- concern about the possibility of surgical complications or side effects from removing the uterus
- concern about the risk for breast cancer (77%)
- doctor's recommendation (64%)
- concern about other side effects of hormones (54%).

We found that a majority of women are not using hormone replacement therapy (HRT) after removal of their ovaries. Many experts agree that HRT or estrogen replacement therapy (ERT) is safe for women under age 50 who have not had breast cancer.

This led us to launch a second survey on decision-making for surgical menopause management. With over 500 respondents, we learned that among women who have never had cancer, 52% are currently taking HRT or ERT, 8% have taken it in the past, and 40% have never taken hormones.

Top factors influencing the decision to take hormones included:

- treating hot flashes (85%)
- age at the time of ovary removal (81%)
- doctor's recommendation (81%).

The top reasons given for not taking HRT included:

When we asked women why they stopped taking HRT/ERT, most cited concern about cancer risk. Regardless of their choice about hormones, a majority of women expressed satisfaction with their decision.

We recently deployed our next engagement survey on decisions around breast cancer risk management, and we are also developing a survey on family communications around hereditary cancer risk.

Check your mailbox

To reach our goal of 12,000 enrollees, we will mail enrollment questionnaires to the entire FORCE subscriber mailing list. Please do your part for HBOC research by completing the enrollment form. If you wish to enroll online and save us postage, you can do so by visiting aboutnetwork.org.

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We so appreciate all of our conference sponsors, whose support helps us to deliver this high-quality program.

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PARP Inhibitor Receives FDA Approval to Treat Ovarian Cancer

by Lisa Rezende, PhD

The FDA has approved Lynparza (also known as olaparib) to treat ovarian, fallopian tube, and primary peritoneal cancer in women who carry mutations in BRCA1 or BRCA2, and who have received three or more chemotherapy treatments. Lynparza is the first PARP inhibitor to be approved, and the first drug that requires patients to undergo testing for a BRCA mutation before they can receive it.

PARP inhibitors are a type of “targeted therapy” that is designed to attack the unique weaknesses of certain cancers based on their biology; a weakened DNA repair system is a shared trait in cancers that develop in BRCA mutation carriers. PARP inhibitors make this problem worse for cancer cells by blocking an enzyme called PARP that cells use to repair damaged DNA. In BRCA-related cancers, PARP inhibitors may work by halting cancer cells from dividing, while sparing healthy cells.

More research is still needed to determine if PARP inhibitors will work in other settings, such as breast and other cancers in people with BRCA mutations. FORCE will continue our efforts to help enroll patients in all HBOC clinical trials, and to ensure that the hereditary breast and ovarian cancer community has access to targeted therapies for all cancers associated with BRCA mutations.

If you or a family member is interested in participating in a PARP inhibitor trial or another research study, please see our Featured Research webpage and/or our HBOC clinical trial search tool at facingourrisk.org/enroll.

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

Primary Peritoneal Cancer: the Forgotten Threat

by Christina Cohen



Christina Cohen

We hear a lot about ovarian cancer, but very little attention is given to primary peritoneal, a related cancer that behaves and is treated similarly. Primary peritoneal is not usually on our radar; women at high risk for ovarian cancer, however, are also at increased risk for this cancer.

Despite its similarities with ovarian cancer, peritoneal cancer may develop even after the ovaries are removed. I know because it happened to me. I had a risk-reducing salpingo-oophorectomy at age 40, and a prophylactic double mastectomy at age 41. Although I was looking forward to a cancer-free future, I remember my doctors saying that these surgeries greatly reduced, but did not eliminate my chance of getting cancer.

At 48, I was diagnosed with peritoneal cancer when my doctor ordered a vaginal ultrasound for my irregular bleeding, and detected a 5-cm tumor growing in the peritoneal cavity near my uterus. This caught me completely off guard. Like ovarian cancer, early-stage peritoneal cancer is difficult to detect because the symptoms are not unique. If you're high-risk, it's important to know your body, and to report any new or unusual symptoms to your health care team.

I am being treated with standard chemotherapy that is used for ovarian cancer. I feel lucky to have a terrific cancer support team at Dana Farber and I am getting the best of care.

A graduate of Vanderbilt and The Wharton School, Christina currently volunteers for non-profits in the Boston area.

Participating in Ovarian Cancer Research

by Sharon Jack



Sharon Jack

I was diagnosed with ovarian cancer in 2009, and subsequently tested positive for a BRCA1 mutation. Following surgery and chemotherapy, I had about 10 months of remission before cancer returned. I then joined a clinical trial for PARP inhibitors rather than have more chemotherapy; if the trial didn't work I could restart chemotherapy. I was anxious that the tumors were growing while I waited for the trial, but I was well-monitored.

As the first human to take a specific oral dose of this particular PARP inhibitor, I was scared but optimistic; I waited anxiously to see if side effects developed, but I didn't feel different. After 10 months, I was happy to be generally living a normal life with no nasty side effects; my cancer shrunk to “non-measurable disease,” and my CA-125 tumor marker went from 204 to 10.

I am very grateful for the trial that gave me a fantastic year without chemo. Although the drug stopped working for me after 10 months, it is still working for others, and I am hopeful that my involvement helps others (I have two BRCA-positive daughters). I have since had more chemotherapy, surgery and other trial drugs with varying levels of success, always hoping that something will target my particular cancer and keep me going. I am now participating in another trial involving a combination of traditional chemotherapy and Carboplatin combined with an ATR inhibitor. Hopefully, this will stop the cancer from growing or even shrink it.

Sharon Jack is a FORCE volunteer dedicated to helping families affected by HBOC.

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.

Ovarian Cancer Research Studies are Looking for Participants

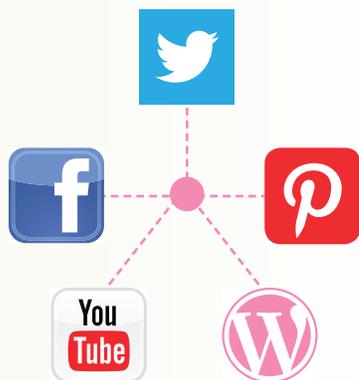
While Lynparza is a huge step for the hereditary cancer community, more work needs to be done. If you are interested in participating in a clinical trial, please go to the FORCE website to find a trial that is recruiting in your area facingourrisk.org/enroll. Some of the featured studies you can learn about include:

- **QUADRA** is a study for women with advanced, relapsed, high-grade serous epithelial ovarian, fallopian tube, or primary peritoneal cancer who have received at least three previous chemotherapy regimens (which may have included a PARP inhibitor).
- **ARIEL2** is a Phase 2 PARP inhibitor trial for women with relapsed, high-grade serous or endometrioid ovarian cancer. **ARIEL2** is now enrolling its expansion phase to include patients who have failed three lines of prior chemotherapy and are platinum sensitive or platinum resistant. All patients enrolled in the study will receive the PARP inhibitor rucaparib.
- **The Consortium for Long-Term Survival**, led by the Mass General Cancer Center and funded by the Department of Defense, is a research group seeking long-term survivors of ovarian cancer. If you are a survivor of eight years or more of stage III or stage IV ovarian cancer, your participation can help to improve the treatment, survival, and survivorship of all women.

Take Our Survey: Media Use by Young Breast Cancer Survivors

Where do you turn to read stories about new cancer research: news websites, television, Facebook? We have launched a survey on media use to assure the XRAYS program reflects media used by young breast cancer survivors and young women at high risk. The survey is brief; it can be completed in about 20 minutes. It will identify the media you use; how much you trust that media; and when, during your cancer risk-management, treatment, and/or survivorship you are most likely to turn to the media.

This survey is open to women age 45 or younger who have had breast cancer or are at high risk for breast cancer due to an inherited mutation in BRCA or other gene, and/or a strong family history of breast cancer. If this describes you, by taking this survey, you will help us learn what sources younger women rely upon for the latest breast cancer information, so that we can assure the XRAYS program meets the unique needs of this population. You can take the survey at <https://www.surveymonkey.com/s/YBCSMediaFORCE>.



XRAYS: FORCE Helps You Make Sense of Cancer Headlines

by Julie Huynh

When cancer makes the headlines, people in our community pay attention. This was clear last fall when Melissa Etheridge claimed in an interview with *AARP Magazine* that people have the power to turn genes such as BRCA1 and BRCA2 on and off. Ms. Etheridge also stated that she would not encourage women to get tested for the BRCA mutations. Her area of expertise is in music, not medicine, but a person of Ms. Etheridge's celebrity has the ability to change public perception. When she says that she caused her breast cancer with a bad diet, or that testing for a cancer risk gene is not what she would do, it has the potential to cause harm. While her case is on the far end of the spectrum in terms of public misinformation, women need a trusted source of information that can review stories in the media for accuracy and relevance. The FORCE community spoke out against Etheridge's misinformation, and we sent a letter that was cosigned by members of our advisory board to *AARP* editors.

While this is a notable case of misinformation on BRCA in the media, it is not the first or last such incident. FORCE has long put new research into context in our "Research Findings" articles, and we have not shied away from spotlighting misinformation. This year, FORCE will combine these two efforts into a formal program called XRAYS (eXamining Relevance of Articles for Young Survivors) program. Funded with a grant from the Centers for Disease Control, XRAYS will

"...women need a trusted source of information that can review stories in the media for accuracy and relevance."

serve as a trustworthy and reliable source for information on the latest cancer research for young women who are at high risk for breast cancer or who are breast cancer survivors.



The breast cancer community is broad and diverse, and not all research applies to all women. People with mutations in BRCA or other genes that are associated with hereditary cancer are at a higher risk for developing more aggressive breast cancer at a young age than those without a mutation. However, young breast cancer survivors and women at high risk for breast cancer are not getting the unique information they need. Often, women over age 45 who have breast cancer need different information than younger women. In some cases, research is more relevant for people with mutations and increased cancer risk than for those who are at average risk. The media does not always clearly define whether research populations involve patients or previvors, the age of the women in the study, or other information that could help women understand if the research applies to their situation.

XRAYS aims to provide survivors of young breast cancer and young women at high risk for breast cancer with quality information on current breast cancer research. The XRAYS program will consider articles that pertain to all aspects of the breast cancer experience, including screening, diagnosis, treatment, survivorship, genetic testing, and risk for other cancers. It will review articles on breast cancer research, rating each for accuracy and relevance. FORCE is excited to launch this program that will help our community understand new research and how it impacts health care decision making. Look for XRAYS reviews starting this fall.

Julie Huynh joined FORCE in January 2015 as a Research Associate for the XRAYS program.

GINA in the Age of Precision Medicine

by Julie Huynh

Does our community feel protected from genetic discrimination or do we still fear it? A perspective article published recently in *The New England Journal of Medicine (NEJM)* addresses these questions and ultimately asks: how successful was the first U.S. federal antidiscrimination statute that was designed to target those two areas?

After over a decade of efforts by FORCE and other advocacy groups, the Genetic Information Nondiscrimination Act (GINA) became law in 2008 with dual purposes: “to fully protect the public from discrimination,” and to “allay its concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research and new therapies.” GINA was precedent-setting legislation, prohibiting employers and health care insurers from discriminating against you based on your genetic information. Extending beyond BRCA test results, GINA protection applies to any genetic information—your own genetic tests, your family’s genetic tests, your family history, or your use of genetic services. This personal information cannot be used against you regarding health coverage or employment.

“To fully protect the public from discrimination”

GINA does have limitations. It does not mandate health care coverage for tests or treatments. It does not apply to discrimination involving life insurance, disability insurance, or long-term care insurance; and it exempts employers with fewer than 15 employees. Given these limitations, are we truly protected from genetic discrimination? Genetic testing is becoming increasingly common, yet as stated in the *NEJM* article, little evidence shows that life insurance companies are requesting or using genetic test results. As the article suggests, GINA may have sent a clear message to all insurers that genetic discrimination will not be tolerated.

Proposed national legislation could weaken GINA and the Americans with Disabilities Act (ADA). The Preserving Employee Wellness Programs Act and proposed U.S. Equal Employment Opportunity Commission (EEOC) changes to ADA would allow employers to ask about personal health information via corporate wellness programs, and allow them to penalize individuals who choose not to participate by sharing this information. FORCE sent a letter

to the House Committee on Education and Workforce opposing this position.

Intersection with the Affordable Care Act

GINA addresses genetic discrimination in health insurance, stating that genetic information cannot be used to determine premiums for individuals or groups. While this was groundbreaking legislation when it was passed seven years ago, the legal landscape regarding health insurance criteria has since changed. The Patient Protection and Affordable Care Act (PPACA) now defines the only factors on which health care premiums may be based: enrollment of you or your family in a plan, age, geographic location of service provided, and tobacco use. Together, GINA and PPACA provide broad protection against health insurance discrimination; health insurers may not discriminate based on a pre-existing condition.

“Allay its [the public’s] concerns about the potential for discrimination”

Does the public know about GINA and understand its full impact? The *NEJM* article discusses a June 2014 U.S. survey conducted with 1,479 people and showing that 79% of respondents did not know about GINA. Among the 21% of people who were aware of GINA, less than half knew that health insurers may not discriminate based on a person’s genetic information, 31% knew that GINA conferred employment protection, and 23% erroneously thought that GINA included similar protection against life insurance discrimination. Unfortunately, after survey respondents read about GINA, 30% were more concerned about discrimination.

The Future of Precision Medicine

GINA was passed to prevent personal genetics from being used in discriminatory ways. This was a definite step in the right direction, but because people are still unaware of GINA, many are hesitant to participate in genomic research that will ultimately provide the key to tailoring uniquely individual treatments. This unwillingness to participate is discouraging when you consider that President Obama’s proposed Precision Medicine Initiative, backed by a \$215 million investment, supports efforts to develop personalized treatments that take into account an individual’s genes, environment

References

Green RC, et al. “GINA, Genetic Discrimination, and Genomic Medicine.” *New England Journal of Medicine* (2015) vol. 372; p. 397-99.

Allain DC, et al. “Consumer awareness and attitudes about insurance discrimination post enactment of the Genetic Information Nondiscrimination Act.” *Familial Cancer* (2012) vol. 11; p. 637-44.

FORCE Supports Precision Medicine

by Lisa Rezende, PhD

FORCE began 16 years ago as genetic testing for mutations in BRCA was becoming increasingly common and families were looking for support, education, and advocacy for a newly forming hereditary cancer community. Members of our community have been using their personal genetic information and family history to make medical decision for the past two decades. FORCE has been a leader in promoting personalized medical decisions based on genetic information, with work that includes:

- advocating for the development of new cancer treatments based on genetic information.
- identifying and addressing privacy issues associated with genetic medicine.
- empowering and supporting patients as they enter the world of personalized medicine.
- creating a patient-powered research network that empowers and encourages patients to participate in all aspects of the research process.

President Obama’s proposed Precision Medicine Initiative will help to bring personalized medicine to more Americans. We applaud this move and we look forward to patient involvement in this important endeavor. Patients can attest to the critical need for more personalized health care; they can also bring important insights into privacy concerns and data sharing, clarity of informed consent for treatments of trials, the need for multiple options for risk management and treatment, and ways to encourage other patients to participate in clinical research. We hope that the Precision Medicine Initiative will bring more patient voices into the conversation, and we look forward to working together to bring personalized medicine to the wider community.

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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.

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GINA in the Age of Precision Medicine *continued*

and lifestyle. Our community is beginning to see the benefits of precision (personalized) medicine with FDA approval of Lynparza for ovarian cancer patients with BRCA mutations. Precision medicine is a step into the future; it holds the promise of better outcomes for everyone who seeks medical treatment, based on their unique genetic makeup. But it is a promise that can only be fulfilled if enough people participate in the research.

FORCE has worked to help our community

understand the protections and limits of GINA since its inception, collaborating with a 2012 study that found that "fear of insurance discrimination" was the second most common reason that people declined testing. We continue to work with genetics and policy experts to ensure that the public understands GINA's protections, so that fear of genetic discrimination does not prevent people from having genetic testing, participating in BRCA-related research, and reaping the benefits of precision medicine.

What's New @ FORCE

Peer Navigator Program Provides Personalized Support

Our soon-to-be-launched Peer Navigator Program (PNP) will provide personalized, one-on-one support and resources for all people facing HBOC. Users need only to complete a short intake form to be matched with a compassionate, trained volunteer with a similar situation.



Peer
Navigation
Program

VolunteerFORCE Academy

The VolunteerFORCE Academy is a new comprehensive online training program that prepares our volunteers to help others who are facing HBOC. Volunteers are trained to provide information, support and resources to help high-risk individuals navigate their healthcare options and make informed medical decisions. The VolunteerFORCE Academy provides training for Peer Support Group Leaders, Helpline volunteers, online message board and chat room moderators, community liaisons, and FORCE Research Advocate Program volunteers who sit on grant review panels and represent the HBOC patient perspective.

