



FORCE ANNUAL REPORT 2014





People Partners Progress

This annual report provides a snapshot of our most important efforts and achievements in 2014. We are proud of our progress and grateful for the partners and people who help us accomplish them. We intend to build on our progress and to maintain momentum on behalf of our community. We hope that you will continue to honor us with your generosity, allowing us to extend our many and varied endeavors on behalf of the hereditary breast and ovarian cancer community.



250,000+

individual visitors to www.facingourrisk.org
website

735

attendees at 8th Annual Joining FORCES Conference

7%

increase in funding to programs this year

We hit the ground running in January, building an infrastructure for the first research registry governed by and for the HBOC community. The ABOUT Network—a collaboration between FORCE, genetic researchers at the University of South Florida, and the Michigan Department of Community Health—is enhancing our capacity to conduct large-scale research studies that are driven by the community we serve.

By year's end we celebrated FDA approval of the first targeted therapy designed to treat cancers caused by a BRCA mutation.

In the busy months between, we educated, supported, and advocated to improve outcomes for all people affected by hereditary breast, ovarian, and related cancers.

While we still have much to do, we are proud of our efforts that unite and galvanize people facing hereditary cancer. We also take pride in our accomplishments, which we could never have done without you! Together, we can accomplish so much more toward recognizing and meeting the unique needs of our community.

People.
Last spring we celebrated

Warm regards,



Sue Friedman
Executive Director



Barbara Pfeiffer
Chief Executive Officer

Living Life Empowered with an intimate gala and fundraising concert by GRAMMY Award-winning singer/songwriter Kara DioGuardi. In June, we brought the spirit of the FORCE community to Philadelphia, hosting the largest-ever gathering of people with HBOC at our annual conference. FORCE's Spirit of Empowerment Award honored Annie Parker as a symbol of courage in the face of hereditary cancer.

Partners.

In 2014, we launched several programs that paved the way for new partnership opportunities. Our research initiatives involve partnerships with genetics researchers at the University of South Florida, the Michigan Department of Community Health, Sisters

Counselors, and Young Survival Coalition. These partnerships help us maximize representation and assure wide dissemination of our work.

Progress.

Last year, our research efforts began paying off. After years of advocacy and promoting clinical trials for HBOC, the first targeted therapy for BRCA-related cancers was approved. We established a mechanism and process for people in the HBOC community to weigh in on important research. In 2014, we extended our already significant reach into the HBOC community, providing nearly 500, 000 people with life-saving information.

Our year culminated with a powerful endorsement for our

FORCE set lofty goals on behalf of the HBOC community, and in 2014 we made unprecedented progress toward them.

Network, Black Women's Health Imperative, Young Survival Coalition, and the Ovarian Cancer National Alliance. We have established strong and influential collaborations that enhance our education efforts, including Living Beyond Breast Cancer, Triple Steps for the Cure, Tigerlily Foundation, National Society of Genetic

work on behalf of everyone with HBOC: we received a CDC grant to help our community understand research reports in the media so that they can make informed medical decisions.

Support

Over 250 men and women gave their time through Volunteer FORCE, empowering tens of thousands of their fellow constituents nationwide in 2014.

Peer to Peer Support.

Our VolunteerFORCE provided support, information, and resources one-on-one and through a network of local Peer Support Groups in 50+ cities nationwide. Our efforts were supported by a 24-hour toll-free Helpline, online message board and community outreach with medical professionals. FORCE's Research Advocates were placed on grant review panels to represent the HBOC patient perspective advocating for our future.

*125+ Events and Conferences
in which our volunteers interacted and
partnered with genetic counselors, health
care professionals, and other nonprofit
organizations*

*Monthly Communications to over 12,000
constituents*

With the largest volunteer support network for the HBOC community, FORCE's Peer Support Group Leaders across the country are able to connect individuals to provide the most comprehensive range of peer support services, including the information, support, and FORCE resources needed to help them understand their healthcare options and make informed decisions. A 24-hour toll-free helpline is available for constituents to speak with a trained volunteer and receive access to the expert reviewed resources they need for their particular situation.

750+ helpline calls

You are Not Alone.

FORCE volunteers ensure that no one travels their HBOC journey alone. We are extremely lucky and grateful to have a dedicated family of volunteers devoting their time to improving the lives of individuals and families affected by hereditary cancer.



FORCE is such a blessing. I am so grateful to benefit from the work of pioneers like the people of FORCE who planted trees so the rest of us could sit in the shade - and so we could feel empowered enough to plant a few trees ourselves.

--Frances Ratner

I became a volunteer in South Florida in February 2011 and have made it my mission to share FORCE's information and resources with others. I am passionate about suggesting individuals can contact a certified genetic counselor, who can correctly counsel them on their own situation. I know from my own story that this information can save your life.

-- Debbie Setuan

I joined FORCE as a volunteer because FORCE helped me tremendously throughout my journey. I know FORCE will continue to help others and I want to be a part of it. I want to educate, empower, and support other families affected by this horrible disease so no one has to go through their journey alone.

-- Christy Thacker



I love to tell people that they are not alone; there is an entire FORCE support network to help them.

--Marisol Rosas, FORCE Helpline Director and Previvor®

FORCE was the single biggest support and resource to me when I was first diagnosed BRCA 1 and continues to be my lifesaver. I want to give back so that no one is ever alone facing HBOC.

-- Annette Seelig

Education

FORCE continues to bring the latest expert-reviewed information to the hereditary cancer community. In 2014 we continued long-standing programs and launched new ones.

Fresh Web Presence.

The launch of our redesigned website with user-friendly navigation, well-defined color-coded sections for education, research, advocacy, and support and improved compatibility with mobile devices.

New Printed Materials.

We launched three new brochures in 2014:

- *What you should know about genes and cancer*
- *Information on BRCA testing for men*
- *Talking about BRCA in your family tree*, developed and produced in partnership with the National Society for Genetic Counselors Cancer Special Interest Group.

8th Annual Conference.

Our 2014 Joining FORCEs Against Hereditary Cancer™ conference, a collaboration with the Basser Research Center for BRCA, featured 48 sessions on all aspects of the hereditary cancer experience, including breast and ovarian cancer detection, prevention, and treatment; nutrition, exercise, and the use of complementary and integrative medicine; managing menopause; networking and information sessions for men, young previvors®, parents, partners, and cancer survivors. Sessions on current advocacy issues and the latest in hereditary cancer research were also included. Over 200 people enrolled in research at the conference, including Basser Research Center's research registry.

Newsletter.

Our Joining FORCEs Against Hereditary Cancer™ newsletter this year featured articles on emerging research and topics of interest to the

hereditary cancer community, including panel testing for multiple genes involved in cancer risk, cancer screening, and ways to accelerate HBOC research.

Be Empowered Webinars.

FORCE brought the experts to the community through our continuing "Be Empowered Webinar" series. Topics this year included:

FORCE has provided my family with information and support that cannot be found anywhere else. I cannot imagine not giving back to FORCE. -- Susan Feinberg

- Newly-Diagnosed with Breast Cancer: What You Need to Know
- Ovarian Cancer 101 for the Newly-Diagnosed
- BRCA and Men: Medical Management and Prostate-specific Considerations
- Screening and Nonsurgical Methods of Prevention for Women at High Risk for Breast Cancer
- The Pros and Cons of Hysterectomy at the Time of Risk-Reducing Removal of Ovaries and Fallopian Tubes

XRAYS.

In September, we were awarded a 5-year grant from the Centers for Disease Control to develop the XRAYS program, a new education initiative where we will rate published reports of new research and write easy-to-understand reviews for the community.

Awareness

FORCE and our constituents have a powerful story to tell. Through the reach of national media we are able to tell that story to hundreds of thousands of people.



THE WALL STREET JOURNAL.



Bringing the Oncology Nursing Community Together

The Philadelphia Inquirer

Partners Helped Spread the Word.

Working with generous firms like Toyota, BFFL Co., Brighton, and Joe's Jeans not only provide much needed financial resources, but help us raise life-saving awareness about hereditary breast and ovarian cancer.

New FORCE Branding Celebrates Our Constituents.

Every day there are stories of empowerment that prove knowledge can be life-saving. Every story shared provides the opportunity for someone else to learn the important messages the hereditary cancer community needs to hear. Great attention was taken in 2014 to revitalize FORCE's appearance based on these stories with a fresher, more user and mobile friendly website, and with a redesign of all of our promotional and collateral materials.

Health Care Provider Awareness.

Since health care providers are in a position to talk to women, men, and families who may have a family history of breast and ovarian cancer, it is imperative that they have current information about HBOC and FORCE to share with their patients. In 2014, 847 certified genetic counselors received our annual mailing, "Empower Your Patients with the Gift of FORCE," which included brochures and informational materials to share with their patients.

Social Media Creates Social Awareness.

Our growing social outlets allow us to share the latest news and information about hereditary cancer. Social shares and comments help spread the word beyond our own community, helping us to create further awareness about the warning signs for hereditary cancers.

It was an enormous pleasure to partner with FORCE this October and share how important women's health issues are to all of us at Joe's Jeans. We are a proud supporter of the fight against hereditary cancer and are grateful for the opportunity to work with such an important organization to help make a difference.

—JOE DAHAN, Founder and Creative Director

JOE'S

Advocacy

FORCE is the leading patient advocacy organization for families affected by hereditary breast and ovarian cancer. Our efforts ensure that the hereditary cancer community's concerns are adequately represented and their voices are heard in the public policy and research advocacy arenas.

Gene Patents and Expansion of Genetic Testing.

As a result of the 2013 Supreme Court ruling which struck down the BRCA gene patents, numerous companies now do BRCA and panel testing for hereditary cancer syndromes. FORCE continued to track and weigh-in on litigation in the BRCA-testing arena. We developed relationships with many of the genetic testing labs and continue to serve as an expert resource for the high-risk community by providing current information about genetic testing, related costs, financial assistance, etc.

Health Care Reform.

The U.S. healthcare system is undergoing substantive changes that impact the availability and provision of health services. The Patient Protection and Affordable Care Act (PPACA) relies on U.S. Preventive Services Task Force (USPSTF) recommendations for guidance on coverage of screening and preventive services. Current USPSTF guidelines on BRCA-related health services have significant gaps that create barriers to genetic counseling, testing, and screening/surveillance services—as well as coverage of prophylactic surgeries—for some portions of the HBOC community. FORCE actively tracks and responds to the

consequences of the guideline gaps, and continues to explore avenues for remedying the situation.

Medicare Coverage of BRCA-Related Services.

Only women who have had cancer and meet specific personal or family history criteria, are eligible for BRCA genetic testing under Medicare. In 2014, FORCE worked closely with members of Congress and relevant government agencies to develop a strategy for expanding coverage of genetic services to Medicare beneficiaries without a personal cancer history who have a family history of HBOC or a known BRCA mutation in the family. We also explored gaining approval of genetic counselors as Medicare providers and coverage of a prophylactic bilateral salpingo oophorectomy for BRCA+ patients. Inroads were made and we will continue our efforts to drive these important changes in the coming year.

Research Advocate Training.

Developed in 2012, the FORCE Research Advocate Training (FRAT) program is an educational course aimed at preparing people to become engaged in research advocacy on behalf of the hereditary breast and ovarian cancer community. The program consists of a series of expert-led webinars and live meetings on topics including breast and ovarian cancer, genetics, statistics, clinical trials and research, patient protection and ethics, and government regulatory processes. The program was expanded in 2014 to meet the growing demand for patient advocates from the HBOC community, and to fill leadership roles in the ABOUT Patient-Powered Research Network.

25 FRAT program graduates serve in advisory roles on cancer research studies, expert working groups, consumer advisory boards, peer review panels, and more.

I participated in the FORCE Research Advocacy Training (FRAT) program, which included a series of expert-led webinars covering topics such as hereditary cancer, genetics, and the research process. This training helped prepare me for my role as a member of the ABOUT Network steering committee. Spearheaded by FORCE and the University of South Florida, this network is part of the federally funded Patient-Centered Outcomes Research Institute that is designed to better engage consumers in the research process. With a close connection to HBOC, volunteering for FORCE has been a transformative experience. I have been inspired by this organization's vision of empowerment—and feel proud of my contributions as a FORCE advocate.

--Brian Honick, FORCE Advocate

Bringing PARP Inhibitors to the BRCA Community.

FORCE has been a strong advocate for PARP inhibitor research for nearly a decade, recruiting for studies, collaborating with pharmaceutical companies and the FDA, and testifying for accelerated approval in an effort to bring this class of drugs to the hereditary cancer community. In December 2014, the FDA announced approval of Lynparza, the first-ever targeted therapy specifically for people with inherited BRCA mutations. We are optimistic that this is only the beginning for this class of drugs. PARP inhibitors are currently being studied for use in other cancer types commonly found in BRCA mutation carriers, offering a promising new treatment option for BRCA-related cancers.

Patient-Focused Drug Development.

FORCE continued its involvement in the FDA Patient-Focused Drug Development initiative via the consumer advisory board. The agency scheduled its Breast Cancer Patient-Focused Drug Development meeting for April 2015 and solicited nominations for fiscal years 2016-2017. FORCE petitioned the FDA to choose hereditary cancers as one of its disease areas during this upcoming cycle.



Research

There is an urgent need to enroll patients into HBOC-specific studies. FORCE connects patients to the HBOC research studies that need participants. In 2014 we launched our Goal to Enroll Campaign to enroll 15,000 people into HBOC research.

ABOUT Network and Patient-Centered Research.

With funding from the Patient-Centered Outcomes Research Institute (PCORI), FORCE and our partners at the University of South Florida and the Michigan Department of Community Health began building the ABOUT Network, the first national research registry created by and for the HBOC community. ABOUT will provide unprecedented opportunities for our community to help drive HBOC research and ensure that research emphasizes finding answers to the questions that we deem to be most important and relevant.

ABOUT is part of the National Patient-Centered Clinical Research Network (known as PCORnet), a resource that will link information and electronic health records for 70 million Americans to their patient-reported outcomes. This platform will accelerate research studies that provide better answers to medical questions and help patients make important medical decisions.

True to the patient-driven concept, ABOUT's governing body, our Steering Committee, consists of people affected by HBOC. We provide the training and a path for anyone from our community who wishes to have a voice in research to complete our FORCE Research Advocate Training (FRAT) Program and apply for a seat on our Steering Committee and Work Groups.

ABOUT Network Partners.

ABOUT is being led by FORCE and researchers from the University of South Florida. We are partnering with other organizations to achieve our enrollment goals, build an inclusive governance structure, and assure diversity and representativeness in all aspects of the ABOUT Network. Our partners will help us promote research opportunities to their membership, assess the information and resource needs of their constituents, and participate on the ABOUT Network Steering Committee. We teamed up with Young Survival Coalition, the Ovarian Cancer National Alliance, Black Women's Health Imperative, and Sisters Network to assure inclusion of a wide and representative population in the network.

A priority of patient-centered research is that patients are involved with identifying which unanswered medical questions are most important to them. We developed our Generate And Percolator (GAP) Tools-- a process to turn community and patient unanswered medical questions into well-

I volunteer with FORCE to make sure no more kids have to grow up without their mother. To make sure women and men don't have to get cancer that can be prevented. To empower others to make educated decisions.

--Heather Clark

The research community looks to FORCE to advocate for and represent the interests of individuals with BRCA1/2 mutations. Critically important clinical trials could not be conducted without the fundamental commitment of FORCE to the development and completion of cancer prevention, detection, treatment and quality of life research.

--Judy E. Garber, MD MPH
Director, Center for Cancer
Genetics and Prevention
Dana Farber Cancer Institute
Professor of Medicine Harvard Medical School

designed research studies. In 2014, as part of our GAP Tool process, we deployed and analyzed results from two engagement surveys in high priority areas for which no medical guidelines exist, the decision about hysterectomy during risk-reducing ovary removal, and the decision about hormone replacement therapy after surgical menopause. The surveys provided insight on how women make decisions about risk-management and showed that one of the biggest influencing factors on patient medical decisions

5,200 Enrolled in the ABOUT Network in 2014

that have no prevailing guidelines is clinician input. These results will guide our design of research studies.

Clinical Trial Matching.

Another area of focus for FORCE this year was to assure that hereditary cancer clinical trials and research studies enroll enough

patients to complete the research. Research studies that cannot enroll enough patients must close, wasting precious dollars and time. Open HBOC-specific clinical trials that desperately need participants must compete with more numerous, larger studies that are not limited to people with a hereditary cancer risk. We built an HBOC research and clinical trial search tool (www.facingourrisk.org/researchtool) that helps to match people facing hereditary cancer with research studies that are specifically designed to understand hereditary cancer. The tool is enriched with studies on cancers related to HBOC: breast, ovarian, fallopian tube, prostate, melanoma, and pancreatic cancers. Studies can be searched by region, cancer site, phase of research, and trial type (prevention, detection, treatment, and quality of life).

Progress in Research.

One of the most rewarding developments came at the year's close. After a decade of efforts educating people about clinical trials, enrolling people into studies, and testifying to the FDA in favor of accelerated access to targeted therapies, we were rewarded with the approval of the first targeted therapy for people with cancer caused by a BRCA mutation. In December the FDA approved Lynparza (also known as olaparib), a type of therapy known as a PARP inhibitor, 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.



2014 Honor Roll of Donors

FORCE is pleased to recognize the generosity of the following individuals, corporations, and organizations who have contributed significantly to our mission, enabling us to continue to support the growing needs of the hereditary breast and ovarian cancer community. Thanks to their ongoing support, FORCE is able to provide lifesaving information, education and support, engaging and empowering families at risk.

Individual Donors

Heritage (\$50,000 and above)

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Joel Hostetter

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Michael Sosin & Tedi Siminowsky

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Generations (\$5,000 - \$9,999)

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Mindy & Jon Gray (co-founders
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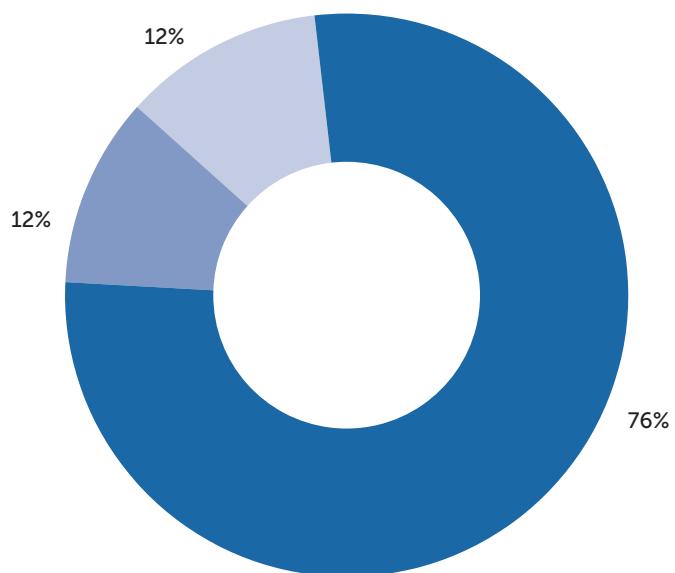
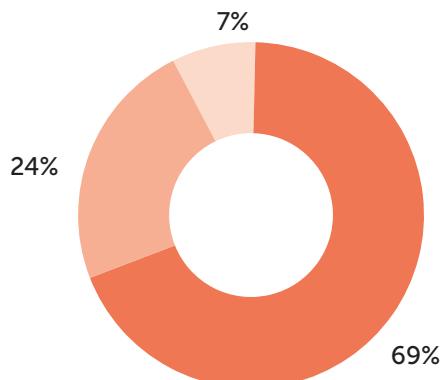
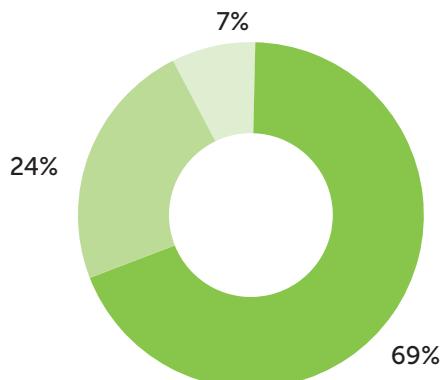
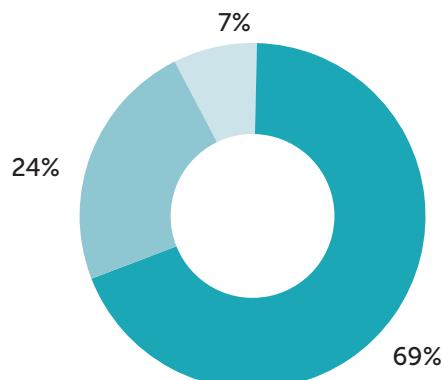
As a BRCA carrier, I have a 50% chance of passing along my mutation to my children. My husband and I have made a commitment to financially supporting FORCE not only because FORCE helped me to face my own risk of cancer in an empowered way, but also because we are committed to ensuring a healthier future for my children and my grandchildren. If by supporting FORCE I can ensure that my children, their children and future generations will be able to live a full life without cancer, then we will continue to make FORCE a priority for our family.
--Jennifer Cole, FORCE Constituent and Supporter



Financials

Revenue & Support		2014
Contributions & Grants		\$1,444,898
Other Revenue		\$4,523
Total		\$1,449,421

Expenses		2014
Programs		\$1,347,961
Management & General		\$218,061
Fundraising		\$212,736
Change in Net Assets		(\$329,337)

2014**Programs** **Management & General** **Fundraising****2013****Programs** **Management & General** **Fundraising****2012****Programs** **Management & General** **Fundraising****2011****Programs** **Management & General** **Fundraising**



Fighting Hereditary Breast and Ovarian Cancer
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