



FORCE Annual Report 2015

In 2015 we focused on building a solid foundation and programs to support the expanding community of people affected by hereditary breast, ovarian, and related cancers (HBOC).

Expanding community

As panel testing made the headlines and more people pursued genetic testing, we were faced with a growing number of constituents turning to FORCE for information, support and research. As options for testing increased and new genes emerged, 2015 also was marked by a need for more personalized resources and support. We updated all our educational materials with expert-reviewed information on panel testing and newly-identified gene mutations and their associated cancer risks. We launched our Volunteer FORCEAcademy, an intensive online training program for our volunteers. Last year, over 100 highly-trained graduates entered our corps of volunteers, prepared to help members of our community navigate the confusing array of medical information and decisions.

Against the backdrop of continued media attention on HBOC, we launched our CDC-funded eXamining the Relevance of Articles for Young Survivors (XRAYS). This program translates articles and reports on emerging breast cancer research into clear and accessible language for hereditary breast and ovarian cancer patients and their loved ones. From our launch in August to the end of the year, we “x-rayed” 17 articles.

Love, voices, choices, future!

As demand for FORCE programs grows, so does our need to build capacity through fundraising. In May, we launched the For Our Children Campaign. With a theme that resonated with the community, this new annual campaign raised over \$150,000 in unrestricted funds to maintain our infrastructure and programs.

Love for our lives

Every year we hear stories about people who were not informed about hereditary cancer in time to protect their health, illustrating why awareness is lifesaving and information is empowering. We launched our KNOW MORE Campaign to educate women with ovarian cancer about genetic counseling and testing, and to help them uncover their medical options.

Voices for our rights

Several emerging issues threatened the rights of the HBOC community or affected peoples’ access to lifesaving medical care. Last year, we fought for continued access to screening mammograms, while working to stop changes that would weaken genetic nondiscrimination laws. We applauded Medicare’s expanded coverage of genetic testing for prostate and pancreatic cancer survivors. Addressing another growing concern—insurance companies denying standard of care services to people with HBOC—we developed a survey to measure the extent of the problem, and drafted templates for insurance appeal letters.

Choices for our health

Research saves lives. It is the only way we can improve medical options for detecting, preventing and treating hereditary cancers. We continued our work to match people from our community to studies and clinical trials that are in need of participants. We received funding from the Patient Centered Outcomes Research Institute to continue the ABOUT Patient-Powered Research Network, a research initiative that allows patients to identify critical research gaps, and help to design research studies to fill these gaps.

Future for our children

Looking beyond the horizon, the future is filled with both challenges and promises. Because of our generous supporters, our efforts will continue with dedication, passion, perseverance, and a vision for a future that is free from the threat of hereditary cancers.

Be empowered and be well!

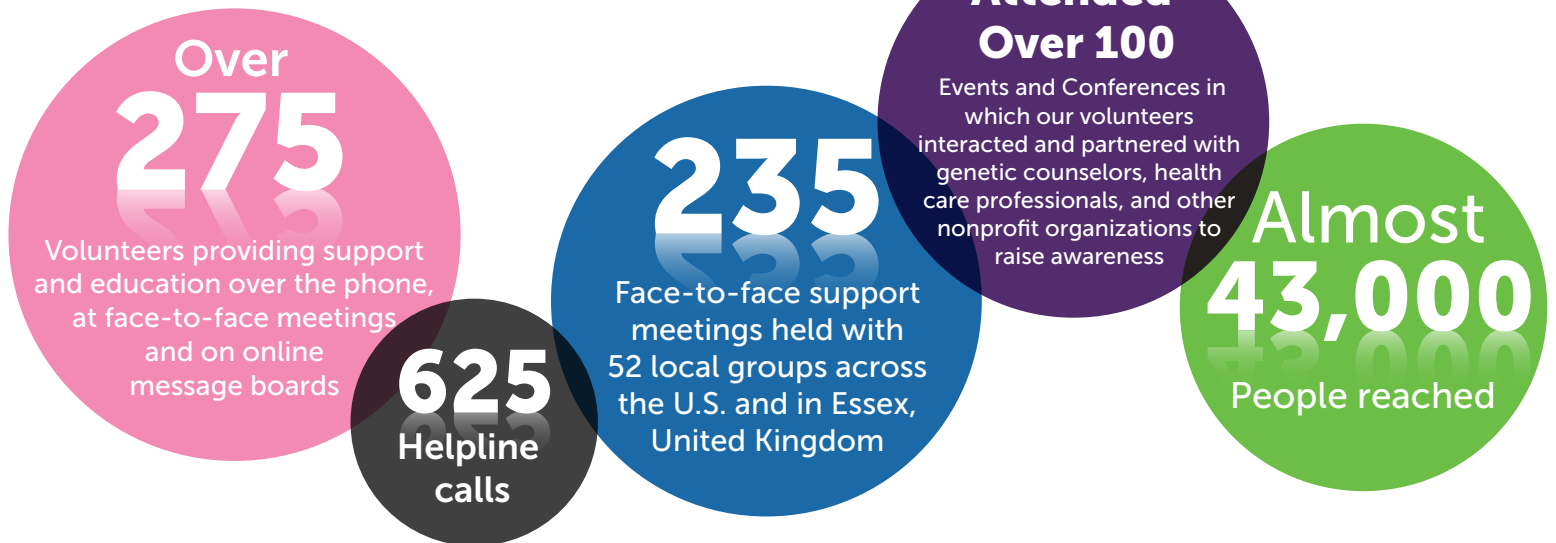
Support

“What a wonderful feeling to know there are women who have walked in my shoes, understand my fears and hopes and are available to share their story and journey with others. ”

- Donna, FORCE Constituent

You Are Not Alone. FORCE recognizes that the hereditary cancer journey is overwhelming and complicated at times. FORCE volunteers ensure that no one travels their hereditary cancer 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.

Support Reach



“Many thanks to you and the FORCE volunteers and staff. You have given the individual faced with hereditary breast and ovarian cancer a valuable resource to navigate through difficult decisions. Your website is excellent. The meeting that I attended in Hershey, PA had a family feel with women sharing laughter and tears. ”

- Lori, FORCE Constituent

“I’m really excited about joining VolunteerFORCE. It makes me feel like I’ll be doing something really important for myself and generations to come. ”

- Tara Haarlander, FORCE Volunteer

New Initiatives Increase Our Impact

- Genetic Expert Affiliate Program provides training to genetic experts interested in starting support groups in their facilities to help people facing hereditary cancer understand their risks and options. FORCE trained four Genetic Expert-led groups to help reach more individuals who need support. We are actively recruiting more genetic experts across the country.
- Peer Navigation Program utilizes a custom database to match individuals seeking support with specially-trained Peer Navigator volunteers, who have travelled a similar journey. This 1:1 support, provided via a single call and email exchange, includes a personalized guide filled with expert-reviewed resources created to empower the individual to make informed decisions with their healthcare team.
- VolunteerFORCE Academy - an intensive interview process and comprehensive series of online webinars and resources that provide knowledge and skills needed to effectively provide non-judgmental support to others - had 130 graduates in its first year!



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“ This program has been a godsend. No one around me is in my specific situation and it’s great to have a place to go where people understand what I’m going through. Thank you. ”

Virginia – Peer Navigation Program Participant

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Awareness Creates Knowledge and Empowerment

83 national
media
spots

reaching over
10 million

50% growth
in social media
reaching

over 30,000
with life saving
information

Over a million

page views of the life saving information
provided via our online database

The Media Widely Spreads the Message

Actress and BRCA mutation carrier, Angelina Jolie, shared (in a New York Times op-ed) her decision to undergo surgery to remove her ovaries. The media called upon FORCE to provide perspective to Jolie's story, bringing a great deal of attention to FORCE and our community.



Forbes



The Washington Post

The New York Times

The Boston Globe

The Philadelphia Inquirer

Healthcare Providers Share the Gift of FORCE

Healthcare providers create awareness and share FORCE information with the patients who need it most. In 2015, 847 cancer genetic counselors received a "Give the Gift of FORCE" package with materials to share with their patients. Additionally, we connected with healthcare providers at the National Society of Genetic Counselors and medical conferences, including the San Antonio Breast Cancer Symposium and the National Consortium of Breast Centers.



New Initiatives Increase Our Impact

KNOW MORE About Ovarian Cancer Awareness

Less attention has been focused on the importance of genetic testing for people already diagnosed with cancer. FORCE's new KNOW MORE: What Every Woman with Ovarian Cancer Should Know Campaign will inform ovarian cancer survivors that they meet national guidelines for genetic evaluation, and help them uncover clues about their health. This new awareness can affect the medical decisions and improve health outcomes for women with ovarian cancer and their relatives.



“ The KNOW MORE Campaign will be critically important in helping make more ovarian cancer survivors aware of the personal benefits of genetic counseling and testing.

I think many women with ovarian cancer think that they don't need genetic counseling because they already have cancer and it won't make a difference. But as a patient who is fortunate enough to currently be taking advantage of one of the new therapies for hereditary ovarian cancer, I know the value of genetic testing not just for me but for my family as well. ”

Teri Woodhull, FORCE Peer Support Group Leader and Ovarian Cancer Survivor

Education

“ Thank you so much. I have been struggling to find a physician knowledgeable in this (hormone replacement therapy) after having surgery and extremely severe symptoms. I hope articles like this help educate doctors and the public. ”

Over 10,000 VISITORS to the FORCE XRAYS Pages

Help, not hype! Launched in Fall 2015, our CDC-funded XRAYS Program translates reports on emerging breast cancer research into language that is clear and accessible to patients. The reviews—published weekly—help readers evaluate the relevance of the research to their situation and the accuracy of the media coverage.



650,000 VIEWS to FORCE Expert-reviewed Hereditary Cancer Information

Over 50 pages of new content, including, panel testing for cancer risk, treating hereditary cancers, and current NCCN guidelines for managing cancer risk.

3,000 page views for our new “Should I consider genetic testing?” page, which launched in September.

80,000 PRINTED FORCE Brochures Distributed

657 PEOPLE Attended the 9th Annual Joining FORCEs Against Hereditary Cancer Conference

The 2015 Joining FORCEs Against Hereditary Cancer Conference® featured over 40 education and networking sessions on topics, including genetic testing, cancer risk management, managing menopause, and hereditary cancer advocacy.





Over 57,000 COPIES of the electronic
Joining FORCEs Newsletter distributed

Over 500 PEOPLE Viewed our 2015 **Be Empowered Webinars**

New topics for 2015 included panel genetic testing, breast reconstruction, and hereditary cancer, insurance, and legal rights.

**Quarterly updates sent to over
4,000 HEALTH CARE PROVIDERS**

FORCE sends quarterly electronic updates to over 4,000 health care providers.

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“ This conference was life changing. I now feel more powerful, more connected to a community, better able to make decisions and more grateful for the knowledge I have. Your work matters so much -- thank you. You are saving lives by empowering us. ”

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Advocacy

“ I think it is great that FORCE is taking a stand to put a moratorium on changes to mammogram and screening guidelines. I was considered average risk, but developed breast cancer at 44. If guidelines would have changed, my early stage cancer could have been more invasive if left for 5 years”

-Wendy

FORCE is the only national nonprofit organization dedicated to fighting for policies and laws that ensure access to lifesaving technology and protecting the rights of people facing hereditary cancers.

Over 35 advocates representing FORCE and the HBOC community served in research advocate positions on Department of Defense and National Institutes of Health grants, state cancer programs, patient advisory boards, ABOUT Network governance and more.

Breast Cancer Screening Guidelines

FORCE was a leader in efforts to curtail raising the minimum age for annual screening mammography to 50. As a key player in the “Stop the Guidelines” campaign and supporter of the Protecting Access to Lifesaving Screenings (PALS) Act, FORCE helped implement a two-year moratorium on changes to existing breast cancer screening guidelines—maintaining free annual mammograms for women ages 40 to 74—while the process for establishing national breast cancer screening guidelines is reconsidered.



Medicare Expansion of Genetic Services

Medicare coverage of genetic testing for mutations associated with increased risk of cancer is very limited. FORCE has continually worked to identify avenues for expanding these services. This year, four Medicare Administrative Contractors, covering 19 states, extended coverage to include BRCA genetic testing for a wider range of people, including men and those affected by prostate and pancreatic cancer, as well as multigene testing panels, when indicated.

Looking Forward

Genetic Information Nondiscrimination Act (GINA)

Proposed changes would allow employer-sponsored wellness programs to utilize financial coercion to encourage participation. It also would weaken protections covering collection of family medical history. FORCE is fighting to preserve the basic protections afforded under GINA.

Cancer Screening Guidelines

FORCE is working to establish a better process for the development of national cancer screening recommendations—which often don't account for the needs of the high-risk community. Ultimately, this may influence which screening and preventive services are covered under the Patient Protection and Affordable Care Act.

In response to reports from our members and health care providers about insurance coverage denials for screening and prevention, we have updated our insurance appeals resources and are creating appeal letter templates. Working with policy experts at the University of North Carolina Center for Genomics and Society, we are developing a survey to document insurance barriers to genetics and cancer preventive care and to ensure that these services are accessible to all who need them.

Striving to meet the needs of the broader HBOC community, FORCE is advocating for insurance coverage of genetic testing for other genes in addition to BRCA1 and BRCA2, and guideline-recommended screening and prevention services.

Collaborations

FORCE works with a variety of organizations to reach the broader community, advance advocacy initiatives and help us achieve our goals. In 2015, we partnered on a number of initiatives, including the ABOUT Network, XRAYS Program, KNOW MORE Campaign, outreach programs and more. We are pleased to work with organizations, including Black Women's Health Imperative, Cancer and Careers, Cancer Support Community, Living Beyond Breast Cancer, Ovarian Cancer National Alliance, Sharsheret, Tigerlily Foundation, Triple Step Toward the Cure, Young Survival Coalition and others.

FORCE also participates in a wide range of coalitions and advisory boards, such as the Metastatic Breast Cancer Alliance, Cancer Innovation Council, CDC Advisory Committee on Breast Cancer in Young Women, and the NCCN Genetic/Familial High-Risk Assessment: Breast and Ovarian Guidelines Panel.

Research

“As a successful participant in a PARP inhibitor study for ovarian cancer treatment, I’m particularly grateful for the work that FORCE has done in ensuring these new treatment options continue to be developed and available to our community.”
– Teri Woodhull, FORCE member and ovarian cancer survivor

8000

people recruited into our
ABOUT Research Registry

44,000

people visited FORCE Research pages

3,400

people visited our matching tool
to find clinical trials

Participation in the design and promotion of HBOC research studies to improve health outcomes

- Recruitment of PARP inhibitor clinical trials as new targeted therapy for people with pancreatic, ovarian, and breast cancer.
- Developed GAP360 – an innovative patient-centered process for identifying gaps in HBOC research and prioritizing research studies.
- Chosen as one of four organizations to receive a Celgene Innovation Impact Award for our proposal to improve clinical trial participation for hereditary breast and ovarian cancer by identifying patients’ information needs around clinical trials and developing more patient-friendly education and clinical trial matching materials.



Participating in Research

ARIEL2: A clinical trial using the PARP inhibitor, rucaparib, to treat women with relapsed, high-grade serous or endometrioid ovarian cancer

BRAVO: A clinical trial using the PARP inhibitor, niraparib, for advanced or metastatic breast cancer patients with a BRCA mutation

Brocade3: A clinical trial using the PARP inhibitor, veliparib, for advanced or metastatic breast cancer patients with a BRCA mutation

CAYA: Cancer Risk and Young Adulthood Study

EMBRACA: A clinical trial using the PARP inhibitor, talazoparib, for advanced or metastatic breast cancer patients with a BRCA mutation

ePOWER: Empowering Prevention Options for Women Experiencing Risk

HEALTH: Healthy Eating & Active Lifestyles Together Survey

MAGENTA: Making Genetic Testing Accessible Study

NOVA: A clinical trial using the PARP inhibitor, niraparib, in the maintenance setting for women with platinum sensitive ovarian cancer

OlympiA: A clinical trial using the PARP inhibitor, olaparib, to treat people with BRCA-associated breast cancer

OlympiAD: A clinical trial using the PARP inhibitor, olaparib, to treat people with advanced, BRCA-associated breast cancer

POLO: A clinical trial using the PARP inhibitor, olaparib, to treat people with advanced, BRCA-associated pancreatic cancer

Quadra: A clinical trial using the PARP inhibitor, niraparib, to treat women with advanced ovarian cancer

RUCAPANC: A clinical trial using the PARP inhibitor, rucaparib, to treat people with advanced, BRCA-associated pancreatic cancer

Survey for Women with a BRCA Mutation and First Degree Relative with Breast Cancer

WISDOM: Women Choosing Interval Salpingectomy with Delayed Oophorectomy to Postpone Menopause

“FORCE has played an important role in the development of research studies for the high-risk community. FORCE has championed research for less invasive methods to lower risk for cancer, such as studying the removal of the fallopian tubes to lower risk for ovarian cancer.”

– Douglas Levine, MD, Head, Gynecology Research Laboratory, Gynecology Service, Department of Surgery, Memorial Sloan Kettering Cancer Center

Supporters

We are extremely grateful to all of our supporters for their belief in our mission, their faith in our efforts, and their outstanding generosity. We regard each philanthropic dollar as potentially life-saving, and we hope that our work will continue to inspire their support and their trust. Without them, we could not do what we do. Thank you.

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Dinah Weable Breast Cancer Survivor Event
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Philoptochos of Virgin Mary
Potts-Dupre, Hawkins & Kramer, Chtd
Saint Gregory the Great School
Theobald Chandler Family Giving Fund
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Weston Cosmetic Surgery

Fundraisers

We are so thankful for our community who turn out every day hosting events, running, biking and reaching out to friends and family to raise critical funding for our life-saving programs.



The Knights of Columbus #3402 Ladies Auxiliary in Keyport, NJ presenting the proceeds from their annual Breast Cancer Awareness BBQ and Basket Auction to FORCE CEO Barbara Pfeiffer.



The Second Annual Cartel Baggers Breast Cancer Awareness Ride organized by our local volunteers featured our very own FORCE car!!



Over 120 devoted individuals answered our call to action for our 2015 For Our Future Campaign. They donated their time, their effort, and their gifts, added their personal touch and together raised over \$115,000.



In celebration of Breast Cancer Awareness Month, Quest Diagnostics and the New York Giants honored longtime fan and FORCE board member, Tara Freundlich, at their home game on October 11.



Attendees at the 4th Annual Hereditary Breast and Ovarian Cancer Ladies' Golf & Tennis Tournament, planned and run annually by Kate Berges.



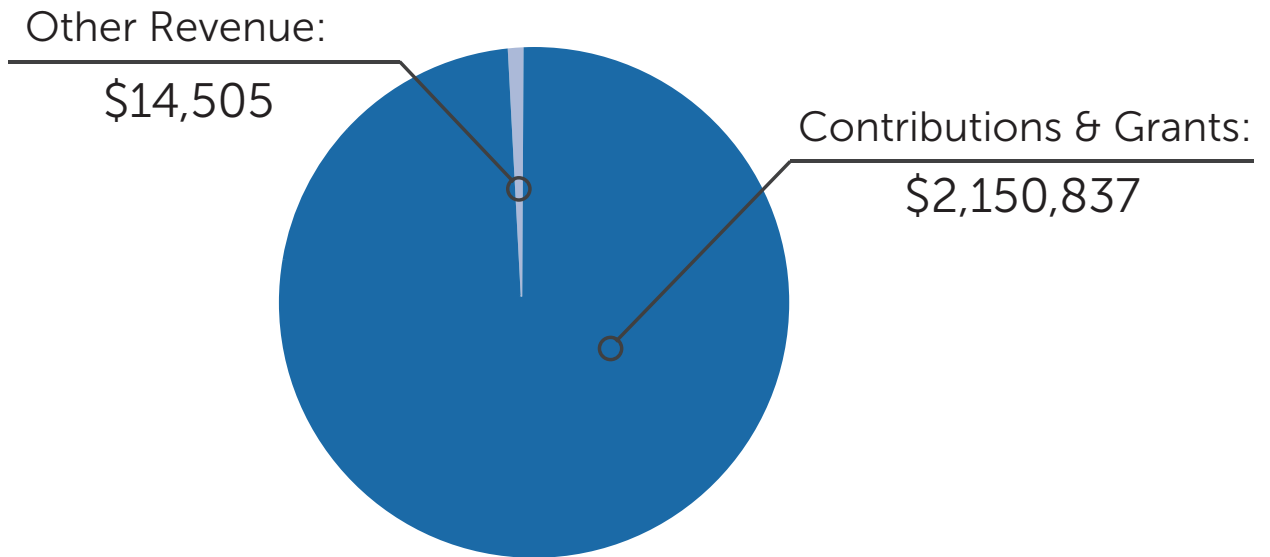
Julie Powers and her Keepers of the Dream team in Franklin, NJ at their third annual walk to raise money for FORCE.



The FullFORCE Philadelphia Dragon Boat team placed in the second division, competing against 140 other teams.

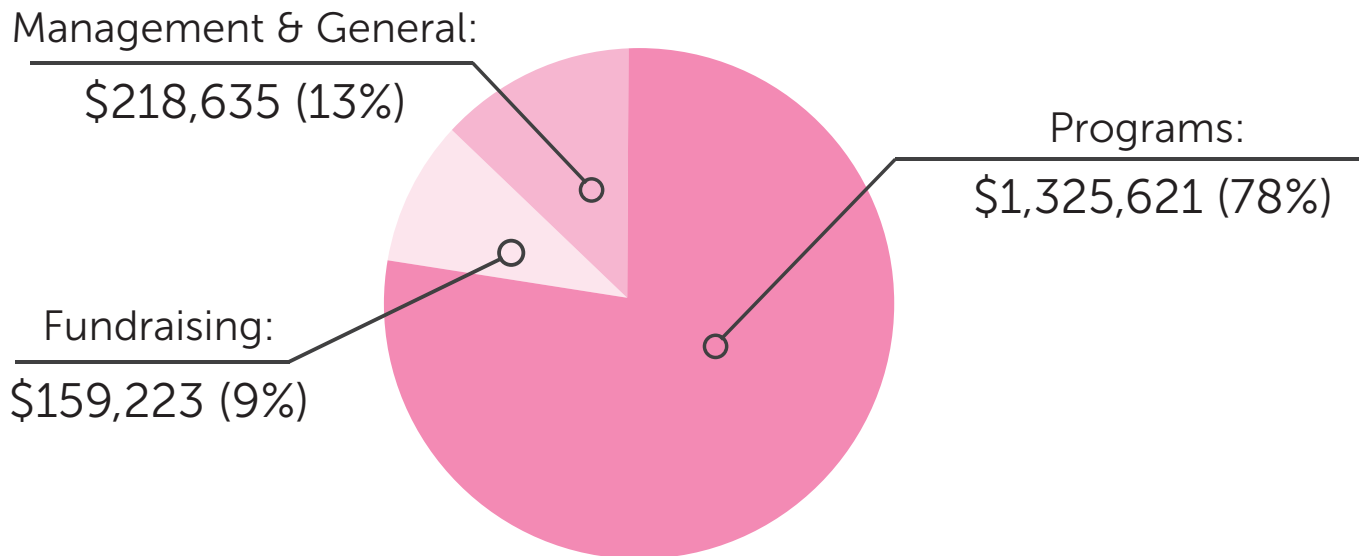
Financials

Revenue & Support



Total: \$2,165,342

Expenses



Change in Net Assets: \$461,863