CONNECTING FAMILIES AFFECTED BY HEREDITARY CANCER WITH HELP AND HOPE

2017 Annual Report
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Thanks to every one of our generous donors, sponsors, staff and volunteers, we achieved new heights and exceeded our goals during 2017. Not only did we reach more people with one-on-one personalized support, information, research and resources, but we also fought for policies and laws to protect all those affected by hereditary breast, ovarian and related cancers.

2017 was full of dedication and hard work, which also means it was full of new milestones for FORCE. Throughout the year, we matched our 1000th Peer Navigation Program user, published our 100th XRAYS review, hosted our 10th annual conference (the only national conference designed by and for the hereditary cancer community), and created the first portal designed to match people affected by hereditary cancer with clinical trials and research studies.

Another landmark of the year was the approval of a PARP inhibitor for the treatment of ovarian cancer. Two large PARP inhibitor studies for hereditary metastatic breast cancer reported improved progression-free survival in patients who took these new agents. FORCE served as an important research partner during both of these promising studies by recruiting patients. The studies are expected to lead to FDA approval of PARP inhibitors to treat hereditary metastatic breast cancer.

Finally, 2017 was a year of growth within our personal team. We grew our staff to 13 full-time and two part-time employees, expanding our ability to improve the lives of the individuals and families we support.

As we enter our 20th year, we are honored and privileged to continue to serve the hereditary cancer community. FORCE still has so much left to accomplish and we are excited about our plans for the future.

Thank you for your ongoing support.
Our Joining FORCEs Conference is the largest gathering of people affected by hereditary cancer and the researchers, healthcare professionals and organizations that support them. Thanks to support from 39 sponsors, and the continued engagement of our community, our 2017 Joining FORCEs Against Hereditary Cancer Conference was a great success. We welcomed 580 participants to the conference and provided financial assistance to 100 people who could not otherwise attend. Attendees represented 35 states and nine countries.

After the cancellation of our 2016 conference due to Hurricane Matthew, most of our sponsors stepped up as “Hurricane Heroes” allowing us to roll over their funding to 2017. It was their generous support that made our 2017 Joining FORCEs Conference possible!
There were so many great topics, I wish the conference was 2-3x as long so I could learn more. Even though this is my third conference, I have been at a different place in my journey and learned more every time. I loved networking and meeting people from around the world; we learned so much from each other.

- Conference Attendee

98% of attendees rated the 2017 conference experience as outstanding or excellent and 97% stated they would attend again.
When I was diagnosed with breast cancer at age 32, I looked on the internet for information and it was exhausting and overwhelming because I didn’t know what was accurate. FORCE’s XRAYS program is so helpful because it takes cancer headlines and puts them into simple terms that anyone can understand.

- Kimberly Jackson, Breast Cancer Survivor
Cancer-related news shared by the media is at times misleading and contradictory. Launched in Fall 2015, our Center for Disease Control-funded XRAYS program translates reports on emerging breast cancer research into language that is clear and accessible to help guide the breast cancer community through all the media clutter.

In 2017, our team of medical experts reviewed, simplified, rated for accuracy and relevance, and published 50 weekly reviews. We celebrated our 100th review – helping readers evaluate the accuracy of the media coverage and the relevance of research to their situation. We presented the XRAYS program at national medical and scientific meetings as well as published an analysis of a survey designed to better understand the information needs and media use by young breast cancer survivors and young women at high risk for breast cancer. It’s all about help, not hype!
FORCE’s Peer Navigation Program matches individuals to a trained Peer Navigator volunteer who shares a similar experience for 1:1 phone support and a free personalized resource guide. Men and women who have either just learned of their predisposition to cancer or have known about it for years can benefit from these critical resources. The program helps to reinforce that no one has to travel this experience alone. Participants now spend less time worrying about how to find information and more time making informed medical decisions.

FORCE’s compassionate Peer Navigator team consisting of 130 trained volunteers, aged 21-75, who share different experiences and genetic mutations are available to help. Health care providers refer patients to this program to help them quickly obtain the information they are seeking. Over 1,000 individuals have been positively impacted by the program since its launch.
It felt so great to empower another person who had a similar experience and give her the resources that helped me so much. When I found out I was BRCA2 positive I constantly wished that I had someone to talk to. It was an amazing experience being that person for someone else.

- Peer Navigation Volunteer
Thanks to a Celgene Innovation Impact Award and support from Genentech, in 2017 we completed creation of the first-ever portal designed to match people affected by hereditary cancers with clinical trials and research studies enrolling people like them. We designed and built a custom database to bring clinical trial information directly to consumers in plain language. Our goal is to assure that critical hereditary cancer research studies can be completed by matching hard-to-reach patients with the studies that desperately need their participation.

This year, two large PARP inhibitor studies, specifically for metastatic hereditary breast cancer, reported improved progression-free survival. FORCE served as a research partner in recruitment of patients for both of these important studies. We are hopeful that these studies will lead to FDA approval for PARP inhibitors to treat advanced hereditary breast cancer in the coming year and are committed to supporting continuing research to ensure our community has better options for treating, detecting, and preventing hereditary cancers.
FORCE was an important partner in driving recruitment to our Phase 3 EMBRACA trial which evaluated a potential new medicine for patients with BRCA-positive metastatic breast cancer. Thanks to the outreach efforts of FORCE and other advocacy groups to increase awareness of this study, we were able to complete study enrollment on schedule. This is a great example of what can be achieved when the oncology community works together to advance drug development.

- Mace Rothenberg, M.D., Chief Development Officer, Oncology, Pfizer Global Product Development

FORCE Research Advocates represented the hereditary cancer community in more than 50 leadership roles with government-sponsored, academic, and industry partners throughout the U.S. Highlights include:

- Alliance for Clinical Trials in Oncology Translational Research Program
- AstraZeneca, Patient Partnership Program
- Bayer, Patient Advocacy Advisory Panel
- BRCA Data Commons Initiative
- Connecticut Expert Genomics Advisory Panel
- Department of Defense Congressionally Directed Medical Research Programs
- Kaiser Permanente, Advisory Council
- National Coalition for Cancer Survivorship, Cancer Policy and Advocacy Team
- Patient-Centered Outcomes Research Institute Advisory Panels
- Research Advocacy Network, Focus on Research Scholar Program
- Society of Nuclear Medicine and Medical Imaging, Patient Advisory Panel
- Stand Up 2 Cancer Ovarian Cancer Dream Team
- Susan G. Komen Career Catalyst Research Grant Program, Reviewer
- Tesaro, Ovarian Cancer Expert Panel and Patient Leadership Council
- University of Pittsburgh Cancer Center, Breast Cancer Research Advisory Network
Patient-Centered Outcomes Research Institute Advisory Panels

- Research Advocacy Network, Focus on Research Scholar Program
- Society of Nuclear Medicine and Medical Imaging, Patient Advisory Panel
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- Tesaro, Ovarian Cancer Expert Panel and Patient Leadership Council
- University of Pittsburgh Cancer Center, Breast Cancer Research Advisory Network
With a new White House administration and shifting national priorities, our advocacy efforts increased significantly in 2017. We established new collaborations and joined coalitions to increase our impact on numerous national issues, as well as state initiatives impacting our constituents. FORCE strengthened its role as a key player in the cancer advocacy arena—and as the leader in representing the unique needs of the high-risk, hereditary cancer community. From genetic privacy and test regulation to cancer screening guidelines and access to care, we advocate on behalf of our constituents, including men, women, previvors, survivors, and people of various ages, ethnic and socioeconomic groups.

Our Year in Review

The breadth and depth of issues we monitor and act upon has increased exponentially. In 2017, we acted to influence policies around:

- Genetic privacy and protections
- Federal research funding
- Oral chemotherapy parity
- Access to state-of-the-art screening and treatment options, such as 3D mammography and PARP inhibitors
- Insurance coverage of high-risk screening and preventive interventions
- Guidelines, policies and regulations related to PSA testing, BRCA testing, multigene panel testing, next-generation sequencing, data-sharing, and more
I just want to thank FORCE...for advocating on my behalf. My teacher’s union denied my paid sick leave stating my surgeries for being BRCA1+ were elective...FORCE wrote a letter to the director of my union and provided information about the gene mutation and national guidelines for BRCA mutation carriers. With your help, we were able to have the director reverse the denial and change the policy for all County employees. From the bottom of my heart, thank you.

- Jill M., Breast Cancer Survivor
In 2017, FORCE spent $1.4 million on programs to support, educate and advocate for the hereditary cancer community.
OVER 2 MILLION web pages viewed

450,000 website visits

over 1,000 pages of expert-reviewed information about hereditary cancer

actively recruited for 23 research studies

65,000 free brochures distributed

specifically focused on hereditary cancers

580 people at Joining FORCEs 2017, the largest conference for people affected by hereditary cancer

249 support meetings

annual XRAYS reviews evaluate the accuracy of breast cancer media coverage and aid in critical healthcare decision making

42 advocates in leadership roles on cancer-related panels and committees

492,000 lives touched
THE POWER OF FORCE Throughout the year, thousands of individuals came together to support our mission. They ran, they danced, they shopped, they exercised, they hosted luncheons and fashion shows... They asked their families and loved ones to join them in their journey to raise funds... And they provided immeasurable support for the hereditary cancer community.
“Good people are like candles – they burn themselves up to give light to others.”
- Unknown

FORCE wishes to thank the individuals, foundations, and healthcare providers who have and continue to support FORCE and enable us to continue our outreach to our ever-growing community.

Annual Donors during the 2017 Fiscal Year
(January 1 through December 31, 2017)

$50,000 to $100,000+
AstraZeneca
Bayer
Celgene
University of South Florida

$25,000 to $49,999
Anonymous to honor Sherry Pedersen
Myriad Genetics Inc.
Michael Sosin and Tedi Siminowsky
TESARO

$15,000 to $24,999
Basser Research Center
COPD Foundation, Inc.
Saul and Theresa Esman Foundation
Hologic
Maralee Schwartz

$10,000 to $14,999
Allergan Foundation
Best Friends for Life (BFFL Co)
Clovis Oncology
Daniel Buckfire
Informed DNA
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Pfizer Inc.
Prevent Cancer Foundation

$5,000 to $9,999
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David and Dory Ellen Fish
Tara and Dr. Kenneth Freundlich
FORCE endeavors to create complete, correct acknowledgement to our supporters. This can be a challenge with a list of this size. If you notice an issue with this list, please accept our apologies and contact us at (866) 288-7475 so that we can correct our records. Thank you.

FORCE Legacy Circle Planned Giving Society

Members of the FORCE Legacy Circle have made a provision in their will or estate plans to help ensure the work of FORCE continues for future generations.

Joel Hostetter*
Karen and Steve Kramer
Sandi and Bruce Ogin
Barbara and Alan Pfeiffer
Michael Sosin and Tedi Siminowsky
Teri and Duncan Woodhull

*deceased