



# 2018 Annual Report

**20 YEARS OF HOPE AND ADVOCACY  
FOR THOSE FACING HEREDITARY CANCER**

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# Table of Contents

Education	4
Research	6
XRAYs	8
Support	9
Volunteers	10
Advocacy	12
TeamFORCE	16
Shopping for Good	18
FORCE Legacy Circle Planned Giving Society	19
Financials	20
Donor List	22





On New Year's Day, FORCE celebrated our 20th Anniversary! It is a tremendous milestone for us. We find ourselves looking back not just at 2018, but at the full twenty years with a great deal of awe in how far we've come and gratitude for the tremendous community that supports us. Together, with the help of our volunteers, donors, staff, sponsors, and every member of our community, we have served as catalysts for change as FORCE has grown into the leading advocacy organization for people facing hereditary cancer. We encourage you to read our blog for a look back at our accomplishments.

As we expanded our efforts in 2018, we saw and continue to see tremendous growth in the use and impact of our programs.

- Our 11th Annual Joining FORCEs Conference was our largest gathering yet, reaching over 725 people affected by hereditary cancer including previvors, people in treatment, survivors, and the researchers and health care providers that work with our community.
- Our Peer Navigation Program DOUBLED its reach this year, offering one-to-one support to over 2,000 participants.
- Through our FORCE Research Advocate Training program, we have trained members of our community to have a meaningful impact on the design and direction of the entire research cycle.
- We published our 152nd XRAYs review, a reliable resource that provides readers with all of the facts and none of the hype on newly published research.
- During our Joining FORCEs Conference keynote, we discussed the importance of personalization: Personalized Medicine, Personalized Resources, and Personalized Support. We are a broad community (and growing) with a shared bond, but unique needs.

Moving forward into 2019, we will continue to not only expand our community to provide more resources and programs for everyone affected by adult hereditary cancers, but also provide greater personalization in our programs so we can better serve our very diverse community.

We are anticipating some exciting changes this year and look forward to continuing our mission of supporting every person affected by hereditary cancer.

Thank you for being a supporter of our mission.

# Education

*“Congratulations on a great conference, and on 20 years of FORCE! It is so amazing to have a great resource to recommend to our patients and families with no hesitation. Your commitment to evidence-based info is so important.”*

*- Lisa Madlensky, PhD*

## JOINING FORCES 2018

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 37 sponsors and the continued engagement of our community, our 2018 Joining FORCEs Against Hereditary Cancer Conference was our largest ever. We welcomed 728 participants to San Diego, our first West Coast conference, providing financial assistance to 114 people who could not otherwise attend, including 24 international attendees.

With the support of Susan G. Komen, we held our first ever Spanish-Language conference program covering a range of topics.

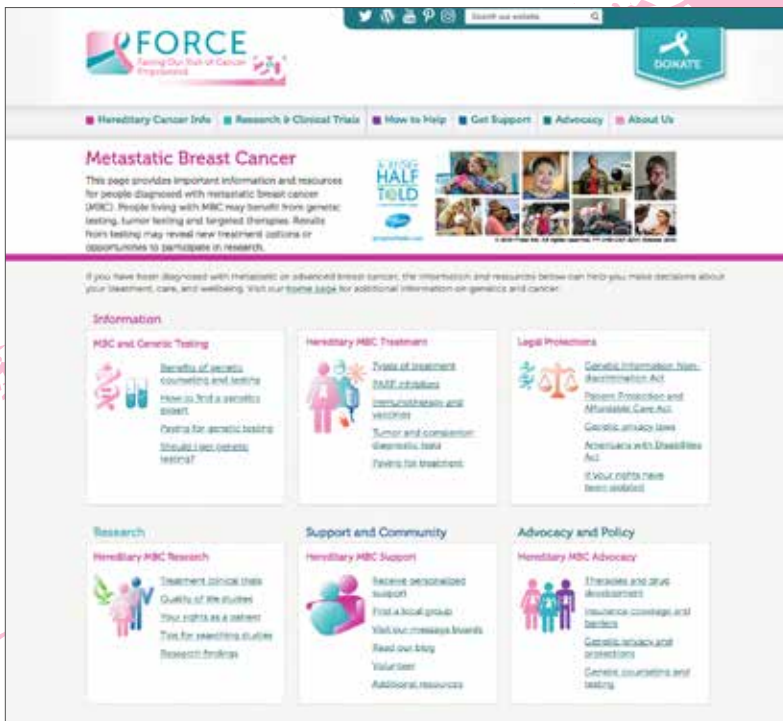


# PERSONALIZED PORTALS GIVE ACCESS TO LIFE-SAVING INFORMATION

For the past 20 years, FORCE has developed the largest expert reviewed database of information on all aspects of hereditary cancer, receiving over 1,000,000 visits annually.

*“I have the BRCA1 gene mutation, and FORCE’s website helped me make many critical decisions which saved my life. The information is invaluable and helped guide me to making very informed decisions. I am now a one-year ovarian cancer survivor and am grateful for the FORCE resources and support.”*

*- Cassie, FORCE Constituent*



Helping people find specific information based on their unique situation is key to making informed decisions.

In 2018, with support from Myriad Genetics and Pfizer, we built our Personalized Portal Page Database and launched our first portal for people living with metastatic breast cancer. Throughout 2019, we will continue to roll out additional portals for ovarian cancer, prostate cancer, pancreatic cancer, and previvors.

*“FORCE provides a tremendous amount of support and in-depth resources to help every person at any stage in their cancer journey make the most informed decisions. FORCE helped me be confident in my decisions and find excellent care.”*

*- FORCE Constituent*

# Research

## NEW DRUGS APPROVED FOR OUR COMMUNITY



*“I greatly appreciate the info on clinical trials. I will probably participate in one since I have recurrent ovarian cancer.”*

*- FORCE Constituent*

In 2018, the FDA approved two PARP<sup>1</sup> inhibitors, Lynparza and Talzenna, for treatment of metastatic breast cancer in people with a BRCA mutation. These marked the first PARP inhibitor approvals outside of ovarian cancer. FORCE assisted with recruitment for the OlympiAD and EMBRACA studies that led to these approvals. In 2018, the FDA also approved the PARP inhibitor Lynparza for first-line maintenance therapy in ovarian cancer treatment, due to the positive results from the SOLO1 trial.

# RESEARCH ADVOCATES REPRESENT OUR COMMUNITY

*“It was very important for me to get involved because I feel I can bridge the gap between the HBOC community and research community. I believe I can be more in tune with the needs or the misunderstandings of the HBOC community, and I can also be a sounding board, or filter when the medical industry wants to connect with our community.”*

*- Marisol Rosas*



Rosemary Ciotti, Society of Nuclear Medicine Imaging Patient

In 2018, FORCE Research Advocates represented the hereditary cancer community in more than 80 cancer research leadership roles with government-sponsored, academic, non-profit organizations, and industry partners throughout the United States. These motivated and passionate advocates help to bridge the gap between patient and research communities.

*“I currently serve on the PCORI Advisory Panel on Clinical Effectiveness and Decision Science. This panel is comprised of patients, providers, and payers. We seek to fund research that will provide evidence for making the best medical choices and get that evidence into the hands of providers and patients.”*

*- Robin Karlin*

## FORCE RESEARCH ADVOCATE PLACEMENTS

- Alliance for Clinical Trials in Oncology Translational Research Program, Patient Advocate Committee
- American Association for Cancer Research Scientist->Survivor Program
- American College of Cardiology, Cardiovascular Function, and Cancer Treatment Roundtable
- American Society of Clinical Oncology Patient Advocacy Program
- AstraZeneca
- Bayer, Patient Advocacy Advisory Panel
- BRCA Commons Data Initiative
- Department of Defense Congressionally Directed Medical Research Programs
- Duke Cancer Institute, Patient Advocate, Clinical Protocol Committee
- Health Datapalooza
- My People Health
- National Coalition for Cancer Survivorship, Cancer Policy and Advocacy Team
- National Ovarian Cancer Coalition
- PaTH Network Advisory Panel
- Patient-Centered Outcomes Research Institute Advisory Panels
- Research Advocacy Network, Focus on Research Scholar Program
- Society of Medical Imaging, Patient Advisory Panel
- Stand Up To Cancer Ovarian Cancer Dream Team
- Susan G. Komen Career Catalyst Research Grant Program
- Tesaro, Ovarian Cancer Expert Panel and Patient Leadership Council
- Triage Cancer
- University of Pittsburgh Cancer Center, Breast Cancer Research Advisory Network

# XRAYs

Cancer-related news is often misleading and hyped. Launched in the Fall of 2015, our eXamining the Relevance of Articles for Young Survivors (XRAYs) program translates breast cancer research into language that is clear and accessible to help guide the breast cancer community through the media clutter.

*“There is so much toxic disinformation in the world of hereditary cancer. FORCE’s XRAYs series is an antidote.”*

*- Judy Wu, My 2¢ op/ed*

In 2018, our team reviewed, simplified, and rated media for accuracy and relevance and published 38 reviews. We shared 10 blog posts related to XRAYs reviews and presented the XRAYs program at medical and scientific meetings nationwide. On November 27, 2018, we published our 150th review - helping readers evaluate the accuracy of media coverage and the relevance of research to their situation. It’s all about help, not hype!



*“Finding out that I carried a BRCA2 genetic mutation was a very frightening experience that made me feel very vulnerable. In my quest to find information about what this meant to me, I was astounded by the sheer volume of confusing information in the media. The XRAYs program summarizes this info into easily accessible articles that put my mind at rest.”*

*- Caroline Presho*



# Support

## VolunteerFORCE REACHES NEW HEIGHTS



Over 300 volunteers are available to provide support and expert-reviewed information and resources to ensure no one faces hereditary cancer alone through eight unique roles. In 2018, our dedicated volunteers reached key milestones:

- Touched the lives of 750,000 individuals via local get-togethers, conferences, message boards, helpline, and personalized peer navigation calls
- Supported 2,000 participants in FORCE's Peer Navigation Program since its launch
- Doubled research advocacy placements to represent the voice of our community with researchers

*“Absolutely wonderful, warm, instant deep connection with my Peer Navigator. I felt an incredible sense of relief during and after our conversation. Best feeling I’ve had since finding out about my genetic mutation.”*

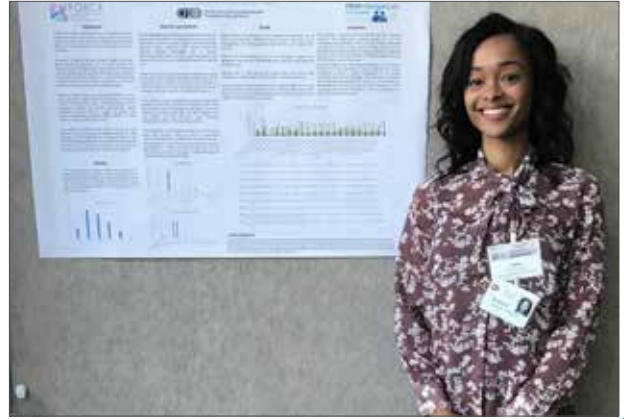
*- Caroline*



# Volunteer Roles



MESSAGE BOARD MODERATOR  
Kelly Iverson



PROJECT  
Ashley Dedmon



PATIENT ADVOCATE LEADER  
Robin Karlin



PEER NAVIGATOR  
Elana Fata



OUTREACH LEADERS  
Dave & Jessie Bushman



HELPLINE  
Annette Seelig



**GENETIC EXPERT LEADERS**

St. Joseph Hospital Center for Cancer Prevention and Treatment



**RESEARCH ADVOCATE**

David Dessert



**VolunteerFORCE TEAM**

*“FOR THE FIRST TIME since receiving my BRCA1 results, I feel like I have a clear path to navigate, supported by an organization and group of individuals that will advocate for the progression of care and patient services that we all need. I truly walked away from a FORCE get-together with a full heart, a wealth of knowledge, and confidence in my plan of care.”*

*- Elise, Constituent*

# Advocacy

## REPRESENTING OUR COMMUNITY

*“A couple years after my BRCA diagnosis, I finally made the decision to start planning for surgery, but my insurance denied coverage. After 3 months of going through the appeals process and still being denied, I felt very hopeless. I reached out to FORCE for help. Two weeks later, the denial was overturned! It feels so wonderful and empowering to have an organization that has your back! Thank you to the FORCE Team! You are saving lives!”*

*- Jessica W.*



### **In 2018, FORCE’s public policy efforts grew to new heights.**

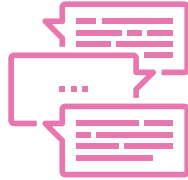
FORCE launched the Patient Advocate Leaders (PALs) program to expand our capacity and strengthen our position as a leader in the cancer advocacy arena. We leveraged partnerships with other nonprofits and health care professional organizations, established new collaborations, and joined coalitions to shape policies that impact the 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.

This year, we monitored and influenced a broad range of policies that impact those with, or at risk of, hereditary cancers:

- Drug pricing models and policies that limit treatment choice
- Genetic privacy and protections in employer-sponsored wellness programs
- National guidelines for identifying and managing people with an inherited predisposition to cancer
- Insurance coverage of genetic testing, cancer screening, and risk-reducing interventions
- Direct-to-consumer genetic tests and marketing by unscrupulous companies
- Federal oversight of diagnostic and laboratory developed tests
- Funding for cancer and genetic research
- Expanded treatment access programs and right-to-try laws

96%

called the **Joining FORCEs** conference experience **"Outstanding"** or **"Excellent"**



53 public relations mentions in major media outlets reaching over 5 million people

Engaged in 40+ state and national policy issues that impact the hereditary cancer community

83

advocates on panels or committees representing our communities' voice in vital research

FORCE touched the lives of **750,535** individuals with our programs



Trained 16 volunteers in public policy to represent our community in critical issues

728 attendees, including 76 faculty speakers from top academic centers, participated in 51 sessions.

# 841

constituents were provided personalized support and a **FREE RESOURCE GUIDE** via the Peer Navigation Program



**488,000 visitors** to the lifesaving information and resources on our website



# 38,000 searches

for research using **OUR RESEARCH TOOL**

We promoted over **50 research studies and clinical trials**

enrolling people affected by an inherited mutation.

These included prevention, early detection, genetic testing, quality of life and treatment studies.



**118,682** free brochures distributed

**300 VOLUNTEERS** available to ensure **NO ONE** faces hereditary cancer alone

# TeamFORCE



*“When you have a passion to support an organization that enriches your life and the lives of countless others, fundraising for that organization is easy. I am not alone. You are not alone. We have FORCE.”*

*- Julie Klein*

We thank those who fundraised for FORCE for the first time in 2018 and we appreciate those who take action year after year to build a partnership that becomes a legacy of love and dedication. Our TeamFORCE fundraisers find ways to make FORCE part of their lives, incorporating their passion with action to support FORCE’s mission.

There are many ways our devoted supporters fundraise for FORCE. Through our Peer-To-Peer campaigns in 2018, our fundraising raised \$164,560.00 in support of our mission. Whether around an event, a personal celebration, or just asking their network to join them in supporting an organization they believe in, FORCE is grateful for these dedicated individuals who continually make the effort to support our mission.



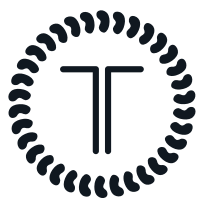




*"I want to give back and be a part of this organization, and running is a great way to do it. Asking my family and friends to support me with my races by donating to FORCE lets me combine the things I love, FORCE and running."*

*- Jan Gronemeyer*

# Shopping for Good



TELETIES

TELETIES are known as the strong-grip, no-rip hair tie that gives back. TELETIES are sleek, stylish, colorful, and fun, but they are not your average hair tie. They double as a fashionable (and stackable) bracelet that is water resistant. With every TELETIES purchase, a donation is made to FORCE. Additionally, every TELETIES package contains FORCE information because TELETIES understands that awareness is power and can save lives.

FORCE is grateful for the support of our retail partners who enable us to raise awareness and improve the lives of those affected by hereditary cancer.



## SISCO•BERLUTI

Sisco + Berluti sells handmade beaded bracelets designed by Boston-based sisters Lisa Sisco and Carolyn Berluti. Their bracelets have been worn by such celebrities as Hoda Kotb, Jessica Alba, Halle Barry, and Michelle Obama and have been featured in *Shape*, *Oprah*, and *Sports Illustrated*. Sisco + Berluti is committed to the fight against hereditary cancers, donating a portion of their proceeds annually to FORCE.



# 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.

Dave and Jessie Bushman

Rebecca and Ken Carr

Sandy and Barry Cohen

Joel Hostetter\*

Karen and Steve Kramer

Dr. Bruce and Sandi Ogin

David Patrick Nixon

Barbara and Alan Pfeiffer

Michael Sosin and Tedi Siminowsky

Teri and Duncan Woodhull

# 2018 Financials

## REVENUE AND SUPPORT

CONTRIBUTIONS

\$1,257,809

GRANTS  
(GOVERNMENT  
AND PRIVATE)

\$771,919

TOTAL

\$2,029,728

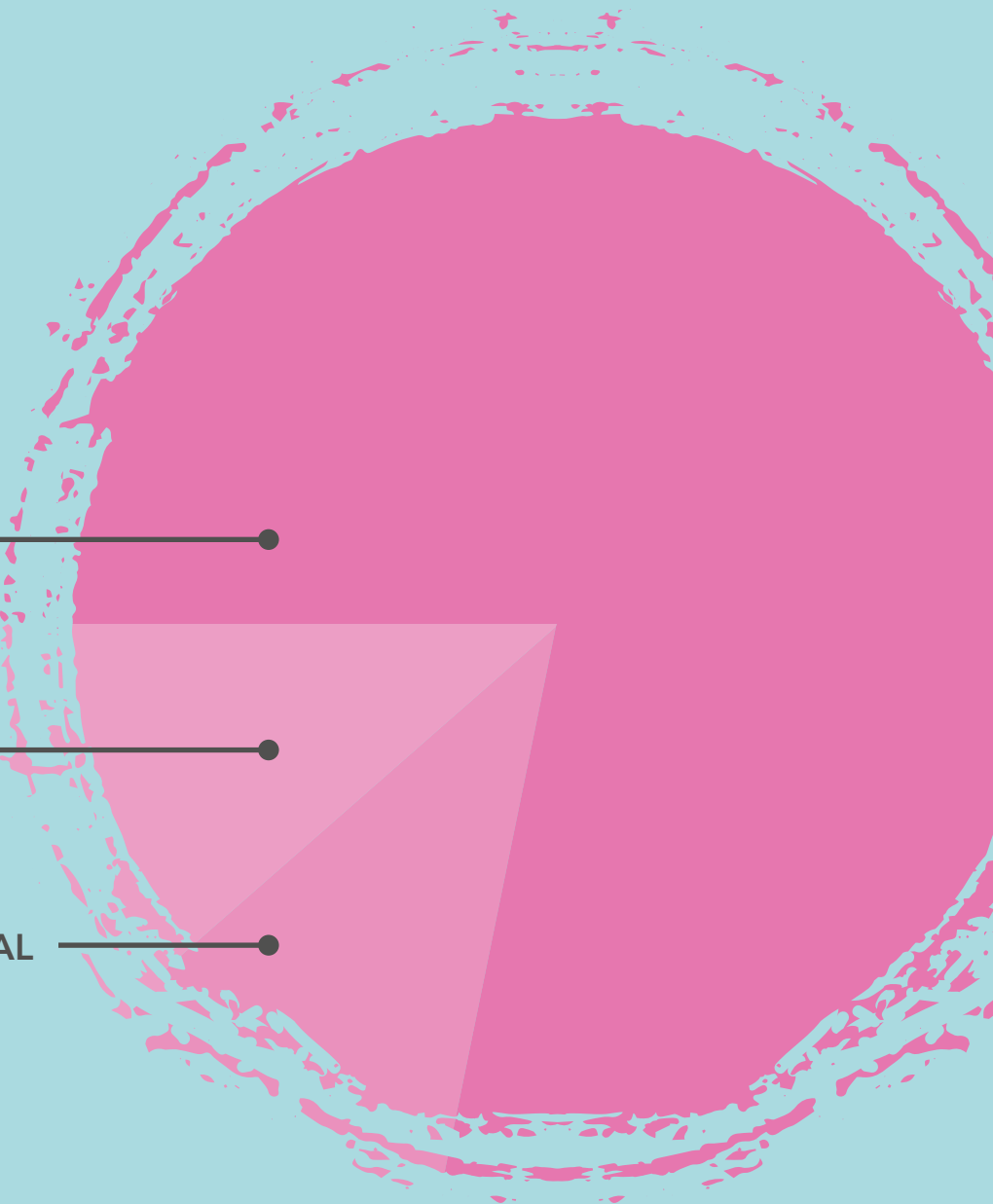
In 2018, FORCE spent **\$1.5 million** on programs to support, educate and advocate for the hereditary cancer community.

## EXPENSES

**PROGRAMS** ————— ●  
\$1,594,482 (78%)

**FUNDRAISING** ————— ●  
\$239,906 (12%)

**MANAGEMENT & GENERAL** ————— ●  
\$192,636 (10%)



# Donor List

## **\$50,000 TO \$100,000+**

AstraZeneca  
Bayer  
Celgene  
City of Hope  
Clovis Oncology  
Novartis Pharmaceuticals

## **\$25,000 to \$49,999**

Anonymous to honor Sherry Pedersen  
Genentech  
The Hamchuk Family  
Myriad Genetics Inc.  
Pfizer Inc.  
Michael Sosin and Tedi Siminowsky  
TESARO

## **\$15,000 to \$24,999**

The Basser Center for BRCA, Penn Medicine  
Center for Restorative Breast Surgery  
Constance M. Chen, MD  
Counsyl Inc.  
Saul and Theresa Esman Foundation  
Quest Diagnostics

## **\$10,000 to \$14,999**

Aetna  
Allergan Foundation  
The Atlantic Philanthropies Director/  
Employee Designated Gift Fund  
Cedars-Sinai Medical Center  
The Cole Family  
Hologic  
Mentor Worldwide  
Prevent Cancer Foundation  
Maralee Schwartz  
Susan G. Komen  
Teleties LLC  
University of California, Los Angeles  
University of California, San Diego

## **\$5,000 to \$9,999**

AbbVie  
Agendia  
AirXpanders, Inc.  
Ambry Genetics  
AxoGen, Inc.  
BD  
Bedford Breast Center, Inc.  
Boston Scientific Corporation  
Eva Bryer and Bardia Pezeshki



**\$5,000 to \$9,999 (contd.)**

Lisa B Cassileth MD, Inc.

Dana-Farber Cancer Institute

Foundation Medicine

Genomic Health

GlaxoSmithKline

Hoag Memorial Hospital Presbyterian

HeritX

Informed DNA

Knights of Columbus Council and Ladies Auxiliary #3402

Joshua L. Levine, MD

Tammy Li

Merck

Andrew Salzberg, MD, Mount Sinai Hospital System

Plastic, Reconstructive & Microsurgical Associates  
of South Texas

Rock 'N Run

Teri and Duncan Woodhull



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