



FORCE Annual Report 2016

Resilience and Fortitude

2016 was a great year for FORCE and the community affected by hereditary breast, ovarian, pancreatic, prostate, melanoma and related cancers (collectively called HBOC). We had many wins and ended the year strong. We launched our long-anticipated Peer Navigation Program, which exceeded all expectations in number of volunteers, users and feedback in the first year.

But 2016 wasn't without its challenges. In October, an unexpected hurricane led to the canceling of our conference. Although it was an agonizing decision, we had to put the safety of our community and faculty first, and we were then able to pivot and secure a 2017 date within an extraordinary time frame.

Towards the end of the year, proposed changes in healthcare policy by the newly-elected administration triggered a period of anxiety among members of our community. In answer to our community's great need for advocacy information, we completed a comprehensive redesign of the advocacy portion of our website and began communicating with our constituents about the steps they could take to assure continued access to care.

2016 also saw the approval of a second PARP inhibitor. This is a great win for our community and we are proud of the role that we played in recruiting for the research that led to FDA approval. None of these gains would have been possible without the great support of our donors, sponsors, Board of Directors, volunteers and talented staff. You are the foundation that built this strong organization to ensure a better future for families affected by hereditary cancer. We are humbled and honored to serve this community and thank you for your commitment and support this past year.



FORCE's Mission is:

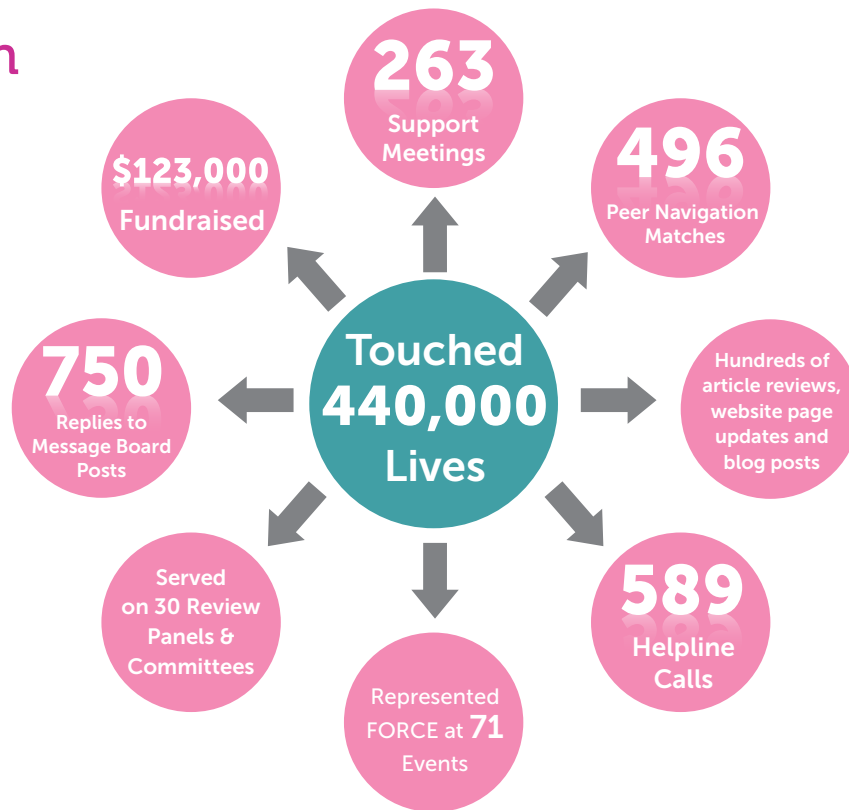
To improve the lives of individuals and families affected by hereditary breast, ovarian, and related cancers.

Support

“This group is informative, caring, and non-judgmental, which is so important, as we each have our own journey and decisions to make. I sincerely believe that we all need each other and, in many cases, this is the only place we can be honest and feel safe with the health concerns we are facing.”

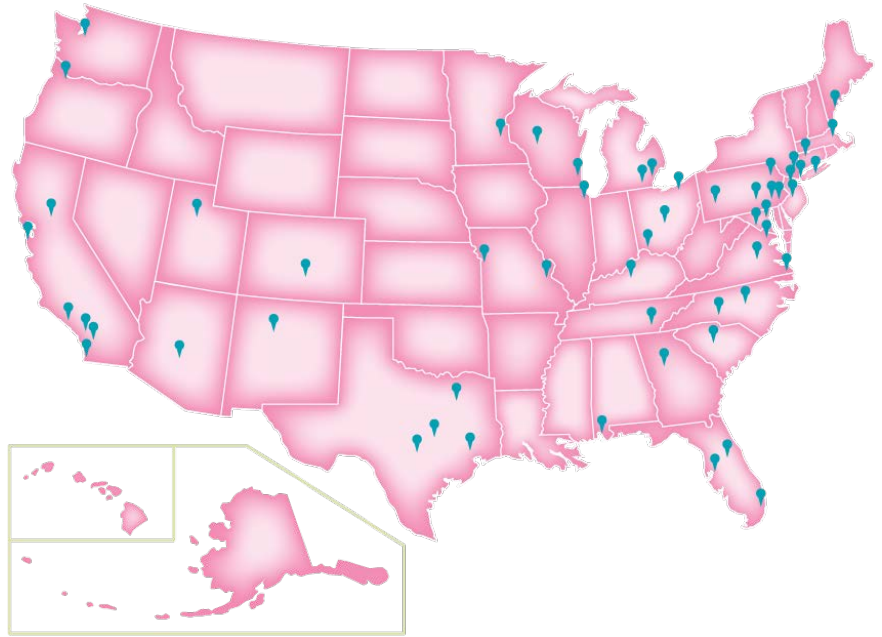
IMPACT: In 2016, VolunteerFORCE Academy trained 196 new volunteers representing 8 different roles. Our 341 highly trained and compassionate volunteers, representing 454 volunteer roles, provide the personal support and outreach to assure that no one has to face hereditary cancer alone.

Support Reach



Reaching Those Who Need Us:

- Peer Support Groups and Expert Affiliate Groups: FORCE has Peer Support Groups that meet quarterly in 45 cities throughout the US and 1 in Essex, United Kingdom. Our Expert Affiliate Groups are located in Palo Alto, California; Orange County, California; Louisville, Kentucky; Scarborough, Maine; Rochester, New York; and Chattanooga, Tennessee.



- Peer Navigation Program: FORCE's Peer Navigation Program (PNP) was developed to provide 1 to 1 individualized support and information to those who need it and who may not have access to a support group in their area. PNP is the result of 18 months of work developing a custom database to match users with volunteers based on demographics, who have faced similar experiences, and a custom platform for personalizing peer navigation pathways for users. Since deploying our PNP program in February, the feedback from users and volunteers has been extremely positive.
- Our newly developed Project Plural fills an unmet need expressed by public health experts to provide high quality information and resources for people in rural areas. Working with partners in three states with large rural populations, we will refine our PNP to meet the unique needs of people facing hereditary cancer in rural regions.

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“ I am so glad that I took the step to see what the Peer Navigator Program was about. My navigator was more than helpful. I had no idea what a relief it would be to talk to someone who TRULY understands what I am dealing with. She was patient, open, and honest, and I am so grateful to have her now as a support! ”

Nichoel - PNP Participant

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“ Many thanks to you and the FORCE volunteers and staff. You have given the individual faced with cancer a valuable resource to navigate through difficult decisions. The meeting that I attended had a family feel with people sharing laughter and tears. ”

Lori – FORCE Constituent

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Awareness Creates Knowledge and Empowerment

36 national
media
spots

reaching over
4 million

60% growth
in social media
reaching

over 36,000
with life saving
information

1,750,000

page views of the lifesaving information
provided via our online database

The Media Spreads our Message Widely

The media continues to call upon FORCE to provide perspective about hereditary cancer, bringing a great deal of attention to our community and FORCE efforts.

FORCE featured in:

CNN

cure[®]

Newsweek

Forward



FASTCOMPANY

The Washington Post

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 2016, 834 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 other medical conferences, including the San Antonio Breast Cancer Symposium and the NRG Oncology meeting.



Awareness Initiatives Increase Our Impact

National Hereditary Breast and Ovarian Cancer Week Creates a New Level of Awareness

National Hereditary Breast and Ovarian Cancer Week and National Previvor Day, created after the passage of a congressional resolution in 2010, generate awareness and recognize those affected by a genetic predisposition to hereditary cancer. Through awareness, the more than 1 million people in the United States who carry a gene mutation can be more proactive with their health and take steps to minimize the impact of hereditary cancer.

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.



“Despite the fact that I had young-onset breast cancer and tested positive for a BRCA2 mutation, and despite my dad’s diagnosis with metastatic prostate cancer, his oncologist told me that men do not carry a BRCA2 mutation. I had to push his doctors for him to get genetic testing. That’s how I found out my mutation came from him.”

Angel Moses, FORCE Volunteer - Chicago, IL

Education

“I am desperate to break the cycle of cancer that has plagued the women in my family. You have been an invaluable resource for making medical decisions and preparing for surgery.”

1 MILLION VIEWS of FORCE Expert-Reviewed Hereditary Cancer Information

12,000 page views for our KNOW MORE: Ovarian Cancer page.

7,600 page views for our “Should I consider genetic testing?” page.

173,000 PRINTED Brochures Distributed

565 PEOPLE registered for our 10th Annual Joining FORCEs Against Hereditary Cancer Conference

The 2016 Joining FORCEs Against Hereditary Cancer Conference® scheduled for October 6-8, 2016 in Orlando was canceled due to Hurricane Matthew. We were fortunate to be able to reschedule our 10th annual conference, held June 8-10, 2017 in Orlando. We are very appreciative of our many sponsors who allowed us to apply their 2016 funding to our 2017 program. We are equally appreciative of our attendees who rolled over their registration to attend our 2017 conference.

OVER 3,000 PEOPLE Viewed our Be Empowered Webinars

New topics included pancreatic cancer, fertility and family planning, and new hereditary cancer clinical trials including the BROCADE3 Study and OlympiA.





Quarterly updates sent to over 4,500 HEALTHCARE PROVIDERS

Over 46,000 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. In 2016 we published 50 reviews— a new review weekly—to help readers evaluate the relevance of the research to their situation and the accuracy of the media coverage.



Over 100,000 people reached through XRAYs Partners

“ XRAYs is a greatly-needed program since the media is not always 100% accurate when reporting medical news. The full text research articles were only available to me on a ‘Pay per View’ basis. ”

Janet – San Diego FORCE Constituent

Advocacy

“ I was denied my paid sick leave, stating my preventive surgeries were elective because I don't currently have cancer. FORCE helped me appeal to the director of my union, providing information about the gene mutation and national guidelines for BRCA mutation carriers. They reversed the denial and changed the policy for all employees in my county. From the bottom of my heart, thank you! ”

In 2016, FORCE took action to influence policy, improve access to care, and protect the rights of the estimated 1 million people in the United States facing hereditary breast, ovarian, pancreatic, prostate, melanoma and related cancers.



NEW ADVOCACY SECTION OF WEBSITE

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.

Advocacy

- What is Advocacy
- Current Issues
 - Genetic Counseling & Testing
 - Genetic Privacy & Protection
 - Hereditary Cancer Awareness
 - Insurance Coverage & Barriers
 - Screening & Prevention
 - Therapies & Drug Development
- Accomplishments
- Resources

Current Issues

Hot Topic

Statement Sets the Record Straight on AHCA and HR 1313
Recent events related to proposed changes in health care and genetic privacy laws have spurred concern and uncertainty in the hereditary cancer community. Some media stories have disseminated inaccurate information, which has intensified people's unease. We prepared [this briefing](#) to dispel some of the misinformation and allay some of the fears that have been expressed.
[Read More](#)

Hereditary Cancer Health Care Report
May 4, 2017
Today, the U.S. House of Representatives passed a bill that would repeal much of the Affordable Care Act (ACA) and replace it with a new health care system. The new legislation allows states to seek a waiver from ACA's current requirement that insurers charge people the same for coverage regardless of whether they have a pre-existing condition. It also eliminates mandatory coverage of essential health benefits such as maternity care, mental health, and preventive screenings. It's important to understand that this is only the first in a number of steps required to change the current U.S. health system.
[Read More](#)

FORCE Weighs In on Prostate Cancer Screening Guidelines
FORCE recently submitted [comments](#) on the USPSTF [Draft Recommendation Statement and Evidence Review](#) for Prostate Cancer Screening. Once finalized, these guidelines are utilized by health care providers to determine appropriate screening and care, and to inform insurance coverage decisions on specific preventive services. The Affordable Care Act stipulates that any preventive service receiving a USPSTF rating of "A" or "B" must be covered by most health plans with no copay or cost-sharing for the patient. Consequently, these guidelines impact access to care for members of the hereditary cancer community.
[Read More](#)

Comments on Draft Research Plan for BRCA Testing Submitted
FORCE recently submitted comments on the USPSTF [Draft Research Plan](#) for BRCA-Related Cancer: Risk Assessment, Genetic Counseling, and
[Read More](#)

New Legislation Threatens Genetic Privacy
H.R. 1313, the [Preserving Employee Wellness Programs Act](#), garnered a great deal of attention in recent weeks. On March 22nd, we received word that

Newsflash

5/23/17
FORCE joined The Ad Hoc Group for Medical Research, representing over 300 organizations, in recommending a \$2 billion FY18 increase for NIH, in addition to funds included in

Preservation of Genetic Protections Under GINA

FORCE was a leader in the coalition fighting new rules proposed by the Equal Employment Opportunity Commission (EEOC) that would weaken protections afforded under the Genetic Information Nondiscrimination Act (GINA). The Commission proposed revising and reinterpreting GINA and the Americans with Disabilities Act (ADA), paving the way for employers to impose financial penalties against employees who choose not to answer Health Risk Assessment (HRA) questions, or to undergo medical exams that are not job-related as part of an employer-sponsored wellness program. FORCE met with government agencies and supported legal action against the EEOC to contest the revisions.

Insurance Coverage and Access to Screening and Preventive Services

Amid increasing concerns surrounding insurance coverage of high-risk screening and preventive services, FORCE teamed up with an academic researcher to conduct an access-to-care survey documenting cases of insurers denying access to lifesaving services, and discussed these obstacles to care with elected officials and regulatory agencies. Results of the survey will be published in the coming year. In the interim, letter templates for insurance appeals were developed on a variety of topics—including genetic counseling and testing, screening and prevention services, and targeted treatment—to assist our constituents in appealing health insurer denials for indicated high-risk screening and preventive services.



Policy Activities

- Oral chemotherapy parity
- Statement to FDA on ovarian cancer screening for high-risk women
- Impact of cost of cancer care
- Contraceptives as preventive therapy for reducing gynecologic cancer risk
- Preservation of Americans with Disabilities Act and Genetic Information Nondiscrimination Act protections in employer-sponsored wellness programs
- Breast density reporting
- Protections for human subjects in research
- Health insurer appeal templates for screening, prevention, and treatment
- FDA oversight of next generation sequencing
- Return of genetic test results and patient rights to access genetic information
- Implementation of precision medicine
- Use of public databases for sharing variant data
- Medicare Part B
- Gaps in the United States Preventive Services Task Force guidelines for screening, prevention, and genetic testing
- Women's Preventive Services Initiative
- Insurance coverage of 3D mammography
- Implications of 2016 elections on access to affordable healthcare services



Research

“As a woman with a BRCA mutation and primary peritoneal cancer, making a decision as to what type of treatment to pursue was a very stressful, anxiety filled ordeal. FORCE helped me discover a PARP inhibitor clinical trial that was taking place in my hometown. After meeting the criteria required, I'm moving along in the trial. This was made possible by the assistance of FORCE.”

10,200
people recruited into
ABOUT research registry

69,000
visitors to FORCE research pages

6,000
people visited our matching
tool to find clinical trials

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

- In 2016, the FDA approved a second PARP inhibitor for the treatment of recurrent ovarian cancer caused by a BRCA mutation. FORCE was an important partner in the recruitment for the studies that led to this approval.
- We completed the design and launch of the ABOUT Patient Powered Research Network website (aboutnetwork.org). ABOUT is a research registry that keeps the patient voice front and center in hereditary cancer research.
- We participated in Vice President Biden's Cancer Moonshot Summit, a collaborative effort involving key cancer stakeholders.
- We were chosen as the patient engagement lead for the Cancer Collaborative Research Group, an initiative from the National Patient-Centered Clinical Research Network (PCORnet).



Research Design and Recruitment Efforts

Recruitment

- ARIEL2: A clinical trial using the PARP inhibitor, rucaparib, to treat women with relapsed, high-grade serous or endometrioid ovarian cancer
- Brocade3: A clinical trial using the PARP inhibitor, veliparib, for advanced or metastatic breast cancer patients with a BRCA mutation
- EMBRACA: A Phase III clinical trial investigating the PARP inhibitor, talazoparib as treatment for metastatic breast cancer in people who carry a BRCA gene mutation
- Follow-up Telephone Genetic Counseling: A study from University of Toronto studying telephone genetic counseling in women who have previously undergone genetic counseling
- Healthy1000: Pathway Genomic's liquid biopsy study for detection of cancer
- Isonohealth survey to guide development of an at-home breast screening ultrasound device
- Mediola: A clinical trial to evaluate the safety, tolerability and activity of an immuno-oncology agent in combination with the PARP inhibitor olaparib in patients with certain types of advanced cancers
- OlympiA: A clinical trial using the PARP inhibitor, olaparib, to treat people with BRCA-associated, stage 2 or stage 3 breast cancer
- Parent Communication Study III: A Georgetown University study to understand the experience of mothers sharing information about hereditary cancer risk with young adult children
- POLO: A clinical trial using the PARP inhibitor, olaparib, to treat people with advanced, BRCA-associated pancreatic cancer
- Short-Term Impact of Surgical Menopause on Cognitive Function in Women at Elevated Risk for Ovarian Cancer: A Cedars-Sinai study on early menopause and cognition
- Study on Latina Women with a BRCA 1 Mutation: A Georgetown study to understand the experiences of Latina women with a BRCA mutation
- SOLO3: A clinical trial using the PARP inhibitor olaparib for platinum sensitive relapsed ovarian cancer in women with a BRCA mutation
- XPANDII: A research study evaluating the safety and effectiveness of an investigational tissue expander

Letter of support

- Genetic Alliance's submission to become the FDA's "National Coordinating Center to Advance Device Evaluation"
- Georgetown University's application "Peer Support for Young Adult Women with High Breast Cancer Risk"
- Kaiser's application "Systems-Level Capture of Family History Data to Assess Risk of Cancer"
- MD Anderson Cancer Center's application "HEALTH 4 Families" to develop healthy lifestyle programs for families at high risk for cancer

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 lifesaving, 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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MD Anderson Cancer Center
University of Toronto
United Health Foundation
Beth Israel Deaconess Medical Center
ITM, Inc
Shalom Club
Post Financial Planning, LLC
Lam Research Foundation

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.



5th Annual Hereditary Breast & Ovarian Cancer Fundraiser at the Pine Orchard Yacht & Country Club with guest speaker Hoda Kotb. The event was planned and run by Kate Berges and her committee.



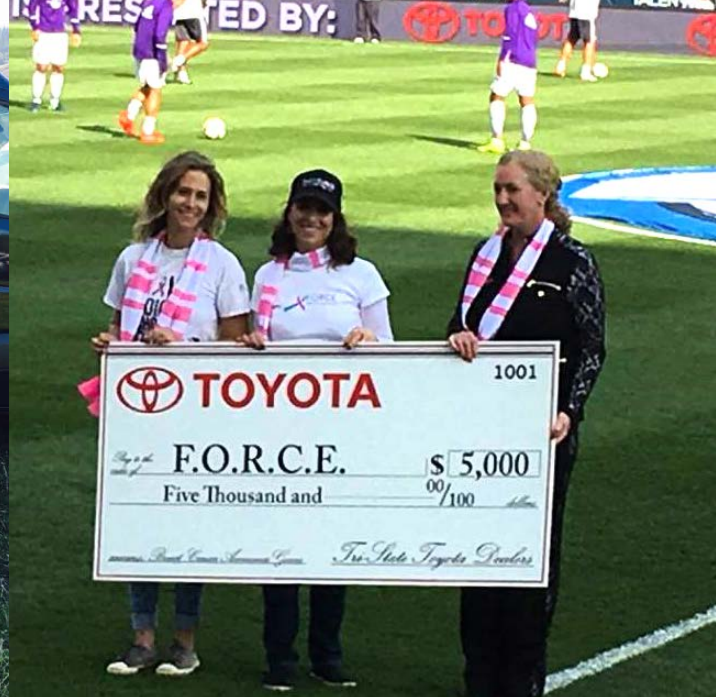
Zoe Richman and Olivia & Abigail Zahl tying Ribbons Around Rye Brook for their Bat and B'nai Mitzvah's and raising awareness and over \$11,000 for FORCE.



In loving memory of mother and wife, Jill Hatfield, Kate, Ben, and Bill Hatfield, ran as a family on TeamFORCE at the 2016 Disney Princess Half Marathon Weekend.



Katrina Wells, Philadelphia/SNJ Peer Support Group Leader, held a fundraising party called "Downing Our Risk" to help beat cancer to the punch prior to her prophylactic bilateral mastectomy, and raised \$4,000.



TeamFORCE Baja completed the Napa Valley Ragnar Relay, running 200 miles in 30 hours. This group of friends pushed their limits, and it was a huge accomplishment for their personal goals and the hereditary breast, ovarian and related cancers community.

6th Annual Philadelphia Union & FORCE Breast Cancer Awareness Night with a \$5,000 check presentation by Pennsylvania New Jersey Toyota Dealers Association.



FORCE Staff walking the talk (or in this case "Running the talk") at runDisney. Left photo, pictured from left to right: Jackie Medina, VP of Operations, Jan Gronemeyer, teamFORCE Ambassador, Sue Friedman, Founder and Executive Director and Ruth Kucharz, VP of Development. Right photo, Jackie Medina poses with Cinderella.

Arriane Spennemann is 11 years old and ran a 5K at Disney in February as a member of TeamFORCE in honor of her grandmother who is a breast cancer survivor.



Ellyn Davidson completing her first half marathon in the Detroit Free Press Marathon. Ellyn celebrated 9 years as a breast cancer survivor and raised \$13,235 for FORCE!



SoleSisters Team completing the Key West Triathlon. Sisters Melanie Herald, Natalie Herald and mother, Lee Ann Herald celebrated the FORCE within t hem and raised \$13,100!



Pictured (left to right) - Julie Klein, Megan Rojo, Laurie Spiegel, Helen Munro-Singleton and daughter Madison Singleton

For Our Future is our annual "friends asking friends" campaign. We thank all of those who joined us in that effort in 2016 by setting up a fundraising page, or making a donation. Together we will make a brighter tomorrow!

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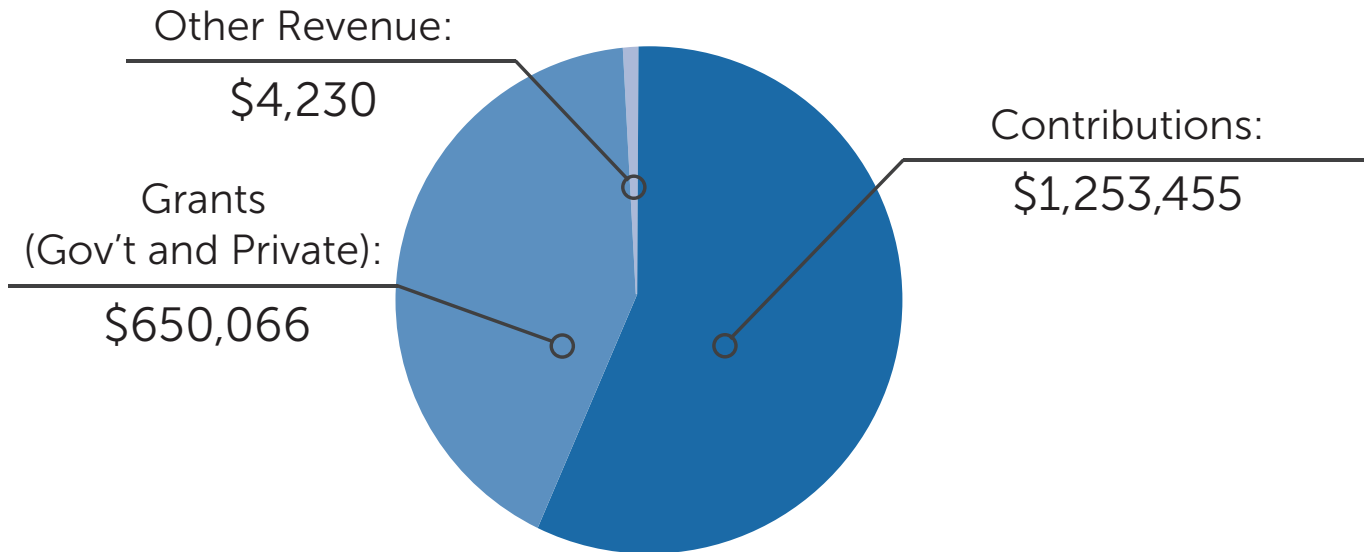
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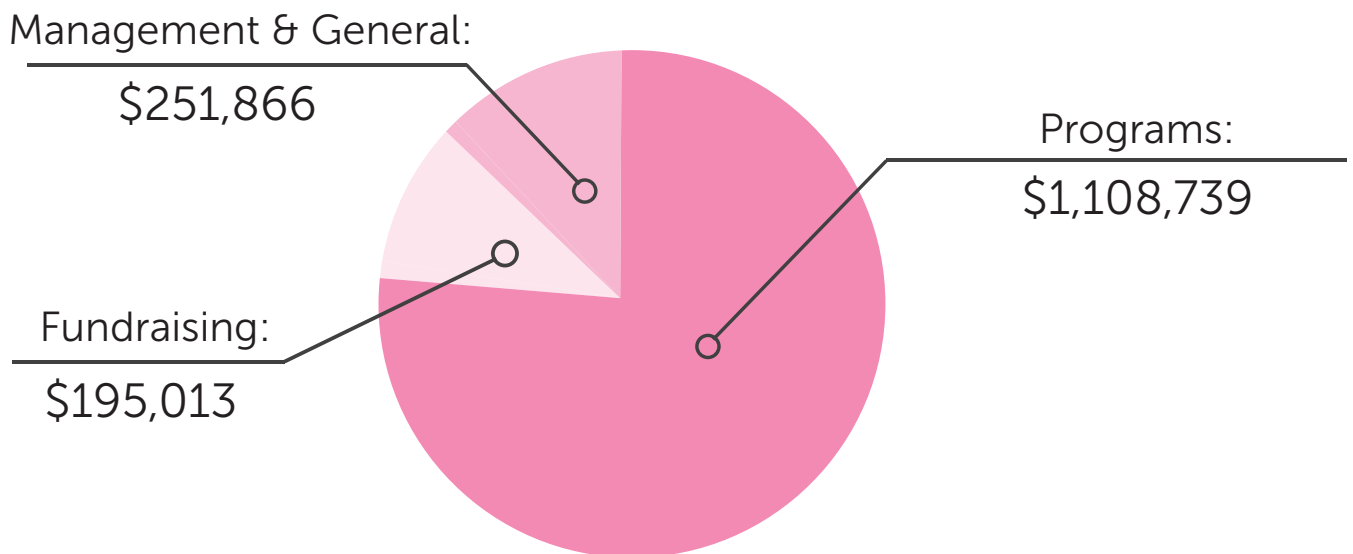
Financials

Revenue & Support:



Total: \$1,907,751

Expenses:



Change in Net Assets: \$352,133

Ending Net Assets for 2016: \$1,146,900