

2019 Annual Report

You may have noticed something new about this year's annual report. Our new logo represents the expansion of our programs and services to support EVERY adult who faces hereditary cancer, regardless of mutation or cancer type.

Advances in genetics research have identified more inherited mutations, many of which are linked to numerous cancers. As a result, more people are pursuing genetic testing and the identified at-risk population for inherited cancers is growing. Now, more than ever, they need our resources and support.

Our enhanced mission statement recognizes this changing, increasing need and underscores our commitment to provide the full strength and scope of our support to all individuals and families who are touched by hereditary cancer or the threat of it.

FORCE improves the lives of the millions of individuals and families facing hereditary breast, ovarian, pancreatic, prostate, colorectal and endometrial cancers. Our community includes people with a BRCA, ATM, PALB2, CHEK2, PTEN or other inherited gene mutation and those diagnosed with Lynch syndrome.

As our community increases, we will work to assure that all of our constituents have access to credible information, compassionate support and high-quality programs across the hereditary cancer care continuum.

We thank you for your continuing support. We could not have achieved this tremendous milestone without it.

Barbara Pfeiffer, Chief Executive Officer
Sue Friedman, Executive Director
Teri Woodhull, President, Board of Directors

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**David Nixon** 

**Director Emeritus** 

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# Education

### **A Trusted Source for Information**



88,647 brochures

distributed free of charge to individuals and healthcare providers.



611,094 visitors

viewed more than

2.3 million pages

on our website and received expert-reviewed information to help make informed medical decisions.

FORCE is acknowledged by healthcare providers as a reliable source of patient information. In 2019, our education team developed hundreds of new and updated pages of content to meet the growing need for credible and expert-reviewed information. These facts and figures provide support and insight that facilitate understanding and help people make informed decisions about their healthcare and risk management options, some of which may be life changing.

We are particularly proud of our newly created content for people with mutations beyond BRCA1 and BRCA2, including ATM, CHEK2, PALB2 and genes that are associated with Lynch syndrome. In addition to breast and ovarian cancers, we now also offer information on pancreatic and prostate cancer.

We also revamped our website, adding portals that streamline navigation and bring related information together, so that we get the right information to the right people quickly, easily and effectively. To date, we've added portals for the following audiences; we will continue to work on this key initiative over the next year:

- Men with metastatic prostate cancer
- High-risk women
- People with pancreatic cancer

Our contributions to publications advance understanding of hereditary cancer among medical professionals.

Collaborating with researchers from Stanford University, we contributed to the scientific knowledge base by publishing results of our survey on genetic testing uptake among women with breast cancer in the *Journal of Oncology Practice*.

Our article, "The Impact of Germline Testing for Hereditary Cancer Post Diagnosis," led a special issue of the *American Journal of Managed Care, Evidence-Based Oncology*™ on hereditary cancers.



Lynch syndrome. We accomplish this mission through education, support, advocacy, and

Published by Kelly Owens, PhD, Lisa Schlager and Piri L. Welcsh, PhD

research.

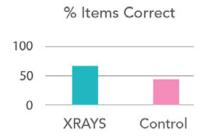
FORCE presented two posters at the 2019 San Antonio Breast Cancer Symposium describing how our XRAY reviews increased understanding of research limitations and information in media reports about breaking breast cancer research.

# Effectiveness of an Online Educational Resource in Increasing Lay Users' *Understanding of Limitations* of Research and Reporting Quality

Robin H. Pugh Yi, Ph.D¹., Piri Welcsh, Ph.D²., Craig Dearfield, Ph.D¹., Kelly Owens, Ph.D²., Lisa Rezende, Ph.D³., Susan Friedman, DVM²

#### **RESULTS: Limitations of Understanding**

The control group, on average, correctly identified fewer than half of the limitations in study methods or reporting, while, on average, the treatment group identified about two-thirds of the limitations in study methods or reporting. The difference between treatment and comparison control groups was statistically significant (p< 0.01).



#### t-test Results

Group	n	Mean Score (s.d.)	t-score (d.f.)	р
Control Group	17	42.85 (19.85)	-3.08 (34)	<.01
XRAYS	19	65.36 (27.66)		<.01

#### CONCLUSI

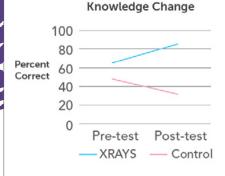
Results indicate compared to a

Effectiveness of an Online Educational Resource in Increasing Lay Users' *Understanding of Information* in Media Reports on Breast Cancer Research

Robin H. Pugh Yi, Ph.D.<sup>1</sup>, Piri Welcsh, Ph.D.<sup>2</sup>, Craig Dearfield, Ph.D.<sup>1</sup>, Kelly Owens, Ph.D.<sup>2</sup>, Lisa Rezende, Ph.D.<sup>3</sup>, Susan Friedman, DVM<sup>2</sup>

#### **RESULTS: Information Understanding**

The control group's knowledge did not significantly change between pre- and post-test, while the XRAYS group's knowledge increased significantly (p<.01), as shown in the table and figure.



#### t-test Results

Group	n	Mean Change in Percent Correct (s.d.)	t-score (d.f.)	р
Control Group	17	-16.47 (35.52)	-3.01 (34)	<.01
XRAYS	19	18.95 (34.94)		

#### **CONCLUSIONS:**

Results indicate that XRAYS is effective in supporting users in learning more factual content from media reports on cancer research than people who read media reports alone. It may be useful to develop similar resources to meet other audiences' needs for information about recent cancer-related research. For this sample, the control group's knowledge decreased, though insignificantly. Given the relatively small sample size of this initial assessment, it would be useful to replicate the study.



We continued to prioritize research and deepened our commitment to increasing options and achieving the best health outcomes for our community.

#### **New Studies, New Approvals**

In 2019, FORCE assisted with crucial enrollment for over 50 clinical trials. These efforts included recruitment for POLO, a clinical trial exploring the PARP inhibitor olaparib for treating pancreatic cancer in people with BRCA mutations. In December, FORCE testified to the FDA regarding olaparib, and we applicated the agency's subsequent approval of this much-needed treatment for pancreatic cancer in mutation carriers. Research succeeds only through participation, and our community's participation in ongoing research has been nothing less than amazing.

FORCE played an essential role in educating patients and families on the association of BRCA and pancreatic cancer and facilitating enrollment in the POLO trial, which successfully tested a targeted therapy as treatment for this disease. Patient advocacy and education groups, such as FORCE, made an important contribution to this trial, and we are extremely grateful for the help they gave us.

—Gershon Y. Locker, MD FACP
Global Clinical Lead, AstraZeneca

Thank you for promoting our prostate cancer screening study on your website.
The turnout has been great, with over 38% of all referrals coming from FORCE!!!

—Anna Couvillon, CRNP
Genitourinary Malignancies Branch
Center for Cancer Research
National Cancer Institute

#### **Amplifying the Patient Voice**

In another significant effort, 49 FORCE-trained advocates represented the hereditary cancer community in more than 140 cancer research leadership roles. These advocates were the voice of the hereditary community at government-sponsored, academic and nonprofit events and with industry partners across the United States. These motivated and passionate advocates help to bridge the gap between patient and research communities.

We continued to build on our previous efforts to include the patient voice and perspective in all aspects of hereditary cancer research. One notable example is our participation in Project Cogent, a collaboration with the University of South Florida. Within the first seven months of this effort, we filled 19 requests from investigators for advocates to participate in research studies.

Project COGENT is supported through a Eugene Washington Engagement Award from the Patient Centered Outcomes Research Institute (PCORI)

Consumer advocates are an integral part of the CDMRP's (Congressionally Directed Medical Research Programs) scientific review process. They provide a key ingredient to the review process—the patient's perspective—which is real and urgent. Consumer advocates alongside the scientists' subject matter expertise is a truly unique collaboration that is difficult to find in most medical research programs.

—David Dessert, FORCE Research Advocate



David Dessert at the DoD CDMRP Pancreatic Cancer Research Program Consumer Review Panel Discussions



Angel Moses at the DoD CDMRP Breast Cancer Research Program

FORCE Research Advocates serve in numerous positions at the national and state levels, furthering our efforts to ensure that the interests of the hereditary cancer community are represented:

- American Association for Cancer Research Scientist<->Survivor Program
- Abridge Research
- Alliance for Clinical Trials in Oncology Patient Advocate Committee
- American Cancer Society Research Scholar Grant Review
- American College of Cardiology, Cardiovascular Function, and Cancer Treatment Roundtable
- American Society of Clinical Oncology Patient Advocacy Program
- AstraZeneca
- Bag It ESCAPE Program
- BRCA Data Commons Initiative
- CA Comprehensive Cancer Control Program
- Cancer and Careers
- Centers for Disease Control FORCE Project EXTRA Steering Committee
- Clovis Oncology
- Department of Defense Congressionally Directed Medical Research Programs
- Duke Cancer Institute, Patient Advocate, Clinical Protocol Committee
- Harvard University
- Health Datapalooza
- InformedDNA
- National Cancer Institute Physical Sciences, Oncology Network
- National Coalition for Cancer Survivorship, Cancer Policy and Advocacy Team
- National Patient-Centered Clinical Research Advisory Panels
- PaTH Network Advisory Panel
- Society of Nuclear Medicine and Medical Imaging Patient Advisory Panel
- Susan G. Komen
- TESARO Patient Leadership Council
- Translational Research Program, Executive Committee of the Alliance for Clinical Trials in Oncology
- Triage Cancer
- University of California San Francisco Center for BRCA Research Program
- University of Pittsburgh Cancer Center,
   Breast Cancer Research Advocacy Network

# Public Policy

# The Voice of the Hereditary Cancer Community



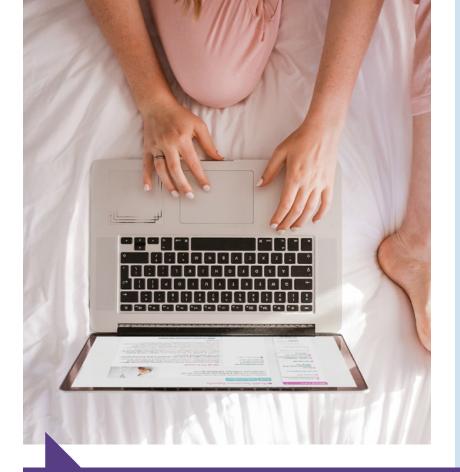
2019 was a pivotal year for FORCE, as the power of our public policy efforts grew to new heights.

We built upon and strengthened our partnerships with other nonprofits and healthcare professional organizations, while collaborating in coalitions to influence policies that affect the hereditary cancer community.

From genetic testing and cancer screening guidelines to genetic protections and access to care, we advocated on behalf of our constituents, including men, women, previvors, survivors and people of various ages, ethnic and socioeconomic groups.

# This year, our work on behalf of those who are diagnosed with or at risk of hereditary cancers included:

- Spearheaded successful efforts to revise Medicare's policy on next-generation sequencing, paving the way for greater coverage of tumor biomarker testing and multigene panel testing for hereditary cancers.
- Advocated to ensure that every state Medicaid program covers BRCA genetic testing. As a result, 47 of 50 states now cover this life-saving test.
- Contributed to dozens of public policy victories, such as securing federal cancer research funding; improving access to cancer screenings, genetic counseling, genetic testing and fertility preservation for those impacted by hereditary cancer; and expanding access to treatment with PARP inhibitors.
- Reported suspected genetic test scams to federal agencies, ultimately contributing to charges against 35 individuals for fraudulent genetic testing and billing practices.
- Played an integral role in efforts to improve labeling, communication and rupture screening guidelines for those who have breast reconstruction with implants.



Men and women in the hereditary cancer community often need earlier, more intensive cancer screenings or risk-reducing interventions that are not recommended for the general population. Insurance coverage challenges for these high-risk services are common. Our sample insurance appeal letters cite national evidence-based guidelines and help to make the case for coverage of services and treatments ranging from breast screening MRIs to pancreatic cancer screenings to risk-reducing surgeries and access to targeted therapies.

Blue Cross Blue Shield finally approved my risk-reducing surgery! I downloaded and sent an appeal letter from the FORCE website, and that's what did it. If anyone is having issues with getting insurance to cover needed screenings or surgeries, definitely head to the FORCE website. I'm high-risk but don't have a BRCA mutation, which I think was part of the problem; FORCE had a sample letter for that. Feeling relieved!

-Susan K., Illinois

I just wanted to extend my heartfelt thanks to FORCE for the assistance provided by their sample appeal letter on "risk-reducing bilateral mastectomy for BRCA mutation carriers" and its reference attachments, as we were just successful in getting an insurance denial overturned on appeal by an independent external review.

My daughter's insurance policy specifically excluded prophylactic services. Thankfully, with help from FORCE, [the insurer] found her planned surgery to be medically necessary and she is now able to undergo this life-saving procedure. It's been a stressful time for our family, but thanks to your wonderful organization, it's now a great deal less so.

—Cynthia K., Florida



# **Empowering Others to Save Lives**

FORCE's volunteer team reached a momentous new milestone, ensuring that more individuals than ever before in the United States, Canada and the United Kingdom were not alone as they faced hereditary cancer. Our 382 dedicated and trained volunteers, who have diverse hereditary cancer experiences, genetic mutations and ages, provided support, comforting words and empowering knowledge in a safe environment to save lives.

836,860

lives touched







382 Volunteers

worked to ensure that no one faces hereditary cancer alone

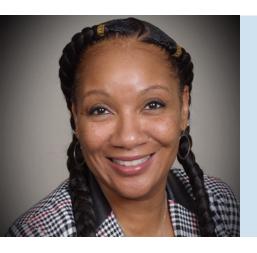
## **Impact by Volunteer Role**



136 Ontreach leaders, including Jeff and Susan Cook, provided local support and resources either by phone, email or face-to-face with constituents for the first time in all 50 states and in Essex, United Kingdom.

21 Helpline Volunteel's, including Rebecca Rabson, spoke with 372 English- or Spanish-speaking callers and provided vital resources and nonjudgmental support regarding finding genetic counselors, genetic testing, financial assistance programs, insurance coverage questions and many additional topics.





**15 Research Advocates**, including Wenora Johnson, underwent 12 hours of training about patient protections in clinical trials, immunotherapy updates, hereditary cancers and treatment options and understanding statistics. During 2019, 49 of these devoted volunteers were placed in 143 advocate opportunities.

56 Project Volunteers, including Judy Wu, were available to assist our Education Department reviewing and developing educational materials for our XRAY program and our website.



## **Impact by Volunteer Role**

**24 Message Board Moderators**, including Elise Travis, connected online with almost 2,000 members of our hereditary cancer community within our General Discussion, Diagnosed with Cancer, Share Your Mutation and Find a Specialist/Doctor boards. These services are a part of our new and improved secure online platform, which includes a free mobile app for convenient, 24/7 access.





192 Peer Navigators, including Scott Lanman, were matched to 1,061 constituents in the United States, Canada and Puerto Rico and shared a free resource guide filled with expert-reviewed information and personalized support over the phone and by email.

Karlena Lara-Otero, Courtney Rowe-Teeter and Rachel Hodan, led face-to-face get-togethers throughout the United States for our community to network and find others locally who share similar experiences.









16 Public Policy Advocates, including Roxana Lopez, assisted in advocating for state and federal level policy issues on behalf of FORCE.

My Peer Navigator was supportive, but also sought my ideas about the subjects at hand. She was so kind and understanding. I cannot adequately explain how much our interaction helped me in looking at things from other vantage points. She was a very positive, encouraging person. She is absolutely the kindest, most supportive woman I've spoken to on this journey. She made me feel safe in sharing ALL matters of concern to me and many I would not even share with good friends I've known for decades.

-FORCE constituent



Our Peer Navigation Program matched 1,061 cancer survivors, people at high risk and their caregivers to trained volunteers who share a similar experience. Our navigators provide support, resources and guidance about recommended hereditary cancer screening, prevention and treatment options. Participation helps individuals make informed medical decisions with their doctors.

I had been gaining valuable info from FORCE for a decade before trying the Peer Navigation Program. The latest discussion with my Peer Navigator was inspiring and helpful. It is so nice to talk to someone who really "gets it."

-FORCE constituent

I am very grateful that this program and personal support are available via FORCE. To be able to discuss issues with an understanding "sister" who is willing to share her own experiences and provide a broad perspective on choices available to me has been incredibly valuable. Especially in these current times in which many forces work to create division among people, I feel blessed that FORCE and the Peer Navigation Program create community, nonjudgmental support, reliable resources and, therefore, hope to people who are facing a challenging health condition. Thank you so much!

-FORCE constituent

As a volunteer, I feel strongly that I benefit from the Peer Navigation calls as much as the callers with whom I'm matched. It is refreshing to know that more and more women are becoming advocates for themselves!

-FORCE Peer Navigator Kristin





We want to thank all of our fundraisers who joined TeamFORCE in 2019 and raised the awareness and funding that allowed us to provide the programs and services that support the hereditary cancer community. They became an inspiration to others to join in our mission by taking action and truly making a difference.

We had many examples of excellence by individuals who put their passion into their fundraising efforts. Below are just a few examples of individuals who made fundraising for FORCE part of their personal mission:

- Carly Miller turned her swim from Catalina Island to Palos Verdes, California into a TeamFORCE fundraising event.
- Annie Brickel, Kirstin d'Incelli, Romane Petit Joseph and Debbie Setuain, our South Florida State Impact Leaders, conducted a Zumba event.
- Jill Rafia created a "Dine to Empower" event at a local restaurant in Encinitas, California, generating awareness and raising funds.

There are many other superstars who helped fund our mission in 2019. We had an army of individuals conduct Facebook fundraisers and set up personal fundraising pages in our "For Our Future" campaign. We had teams and individuals participate in athletic events and run at a *run*Disney event as a member of TeamFORCE. We thank every fundraiser who partnered with us to raise funds in 2019. Together, their efforts generated over \$174,000. We greatly appreciate you putting your passion into action in support of our mission.

As difficult and emotional as it has been to live with the knowledge that I have passed this gene mutation on to my children, I, unlike my mother who died at a young age, had a choice. My children, through their respective journeys, have had choices. My grandchildren, should they test positive, hopefully, through the research with which FORCE is involved, will have even more and better choices.

—Annie Brickel, FORCE Volunteer







FORCE supported me and helped me connect to a network of doctors and make friends who have faced similar choices to what I have had to face.

-Jill Rafia, FORCE Volunteer

# Thank you to the individuals, foundations and corporations who have donated to further our mission.

#### \$25,000 and above

Allergan

Anonymous to honor Sherry Pedersen

AstraZeneca

Basser (University of Pennsylvania)

Celgene

Clovis Oncology

Foundation Medicine

Genentech

Pfizer Inc.

Saul and Theresa Esman Foundation

Susan G. Komen

TELETIES, LLC

*TESARO* 

The Allergan Foundation

#### \$10,000

Bristol-Myers Squibb Company Jason Lustig and Destin Black Maralee Schwartz Michael Sosin and Tedi Siminowsky Tammy and John Li

#### \$5,000 - \$9,999

Eva Bryer and Bardia Pezeshki

Genomic Health

Hologic

Jeffrey and Rebecca Zindel

Knights of Columbus Council

and Ladies Auxiliary #3402

Leslie Rose

Leslie Seeman

Mary Stranahan Foti and Anthony Foti,

in memory of Marilyn Stranahan Burtner

Rebecca Sutphen and Norma Nixon

Rock N Run

Sisco + Berluti

The Cole Family

#### \$1,000 - \$4,999

Allen and Kate Rhinehart

Anne Robinson

Annette and Robert Seelig

Anonymous

Barry and Sandy Cohen

Bill and Eva Roche

Brighton Retail

Brown-Carrigan Family

Cari Roth and Wellington Meffert

Carolyn Koutsaftis

Daniel Buckfire

Dave Goetsch

David Dessert

David Nixon

Diane and Thomas Rose

Dr. Kenneth and Tara Freundlich

Elaine and John Kennedy

Evelyn Philipps

Hartford Foundation for Public Giving

HSN LLC

Ilana DeBare and Sam Schuchat

Jan, Paul and Paine Gronemeyer

Jane Schapiro Brown and Scott Brown

Janet Damaske

Jody Gunn

Kristine Schannauer

Laura Baron Bellome

Linda Shecter

Lois and Peter Pardoll

Margaret Hardy

Margaret Stewart and Severin Borenstein

Mark and Joan Roby

Melanie Herald

Michelle and Jonathan Barsook

Midwest Breast & Aesthetic Surgery, Inc.

Myles Brown and Dr. Judy Garber

Neil and Joan Okun

Patricia Stahl

Rebecca and Kenneth Carr

Richard and Marilyn Kossik

Robert Sica

Stephen and Janet Groft

Steven Davis

Susan and Lex Goldenberg

Tankenoff Families Foundation

Teri and Duncan Woodhull

The Community Foundation Serving SW Colorado

The Denver Foundation

The DuPage Foundation

The Women's Care Florida Foundation Inc.

Theobald Chandler Family Giving Fund

Thomas Kessinger

William Stewart

Yourcause, LLC

## **Multiplier Fund**

Thanks to a generous group of supporters, a multiplier fund was established to match all donations to FORCE in November and December, doubling the impact of the 2019 year-end donations. Together, more than \$200,000 was raised to support the hereditary cancer community. FORCE wishes to extend our heartfelt gratitude to the Multiplier Fund lead donors for contributing to the \$100,000 matching gift and to the hundreds of individuals who so generously gave to help us achieve our goal. Thank you for making a difference!

To learn how you can join the group of 2020 Multiplier Fund Donors, please contact **Donations@FacingOurRisk.org**.

#### **2019 Multiplier Fund Donors:**

**Anonymous** 

Anonymous gift to honor Sherry Pedersen

Michelle & Jonathan Barsook

Wendy B. Bloom

Brown-Carrigan Family

Eva Bryer and Bardia Pezeshki

Jeff and Susan Cook

The Saul & Theresa Esman Foundation

Mary Stranahan Foti

Bruce Forstall

Jodye and Peter Glick

Lois and Peter Pardoll

Bill and Eva Roche

Leslie Seeman

Linda Schecter

Ilana DeBare and Sam Schuchat

Michael Sosin and Tedi Siminowsky

Teri and Duncan Woodhull

Sarah and Andrew Yeung



## **Legacy Circle**

The FORCE Legacy Circle honors especially charitable individuals who have included FORCE in their estate plans. Their commitment allows us to plan for the future and to ensure that the next generation of individuals facing hereditary cancer has the support it needs.

Dave and Jessie Bushman Rebecca and Ken Carr Sandy and Barry Cohen Joel Hostetter\* (Deceased) 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

Please let us know if you have named FORCE in your will or trust, so that we can add you to our Legacy Circle and share relevant updates with you. We pledge to protect your name and gift in strict confidence if you wish to remain anonymous.

## **Shopping for Good**

FORCE is grateful for the support of our retail partners whose generosity makes it possible for us to raise awareness and improve the lives of those who are affected by hereditary cancer.

TELETIES are known as the strong-grip, no-rip hair tie that gives back. TELETIES packaging shares FORCE information, and FORCE receives a donation with every purchase.

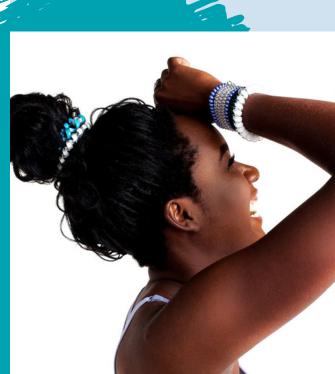
Sisco + Berluti sells handmade beaded bracelets worn by Hoda Kotb, Jessica Alba, Michelle Obama and other celebrities. The company is a long-time supporter of FORCE, donating a portion of each product's sale to us.

# SISCO BERLUTI



TELETIES





# Financials

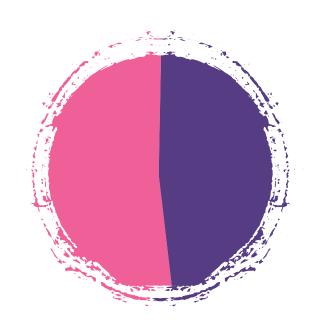
In 2019, FORCE spent more than \$1.3 million on programs to support, educate and advocate for the hereditary cancer community.

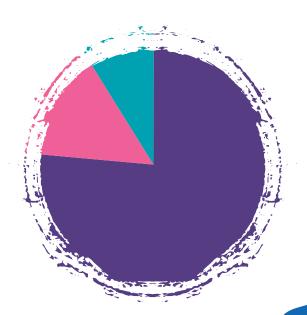
## **Revenue and Support**

Contributions: \$976,241

Grants (Government and Private): \$1,021,035

Total: \$1,997,276





# **Expenses**

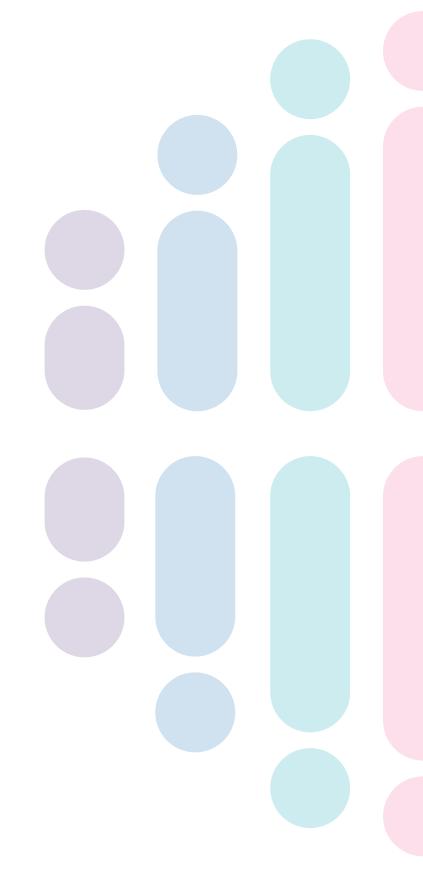
Programs: \$1,364,619 (80%)

Fundraising: \$195,348 (11%)

Management and General: \$150,289 (9%)

Total: \$1,710,256

Net Assets beginning of year: \$916,900 Net Assets end of year: \$1,206,381 Change in Net Assets: \$289,481



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