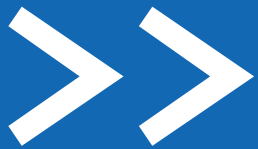




Facing Hereditary Cancer EMPOWERED

2020 Annual Report



An unforgettable year

2020 was one of the most challenging times in recent history. Due to the COVID-19 pandemic, our country, our communities and each of us had to adapt to frightening and challenging circumstances. But, with many changes, also came the opportunity for profound growth.

With the help of our board of directors, volunteers, healthcare providers and generous donors, we adapted and expanded. We created new programs and support options to accommodate the hereditary cancer community during changing times. We accomplished this all while achieving our special milestone on October 6, 2020, when we launched a bigger, better FORCE that serves so many more.

FORCE

Facing Hereditary Cancer **EMPOWERED**

Our new website and our new logo are reflective of our expanded community that has moved beyond pink and teal to now include anyone who faces hereditary breast, colorectal, endometrial, ovarian, pancreatic and prostate cancer as a result of an inherited mutation in a BRCA, ATM, PALB2, CHEK2, PTEN, Lynch syndrome or other high-risk cancer gene.

“I feel as though I have hit the jackpot, because with FORCE, I am able to gain more knowledge about this syndrome and share the information with others just like me.”

WENORA JOHNSON

Lynch Syndrome Colorectal and Endometrial Cancer Survivor



“While I have never been embarrassed about my breast cancer, it is a very hard cancer to navigate as a man. FORCE is an amazing organization that helps so many previvors and survivors.”

HARVEY SINGER

BRCA2 Breast and Prostate Cancer Survivor



The launch was accompanied by an extensive awareness campaign across all digital channels, driven by the unique stories of our constituents to show the breadth of our community and services. These voices demonstrate that no matter what your mutation or diagnosis, FORCE is here for you.



Focused attention on diversity, equity and inclusion

The murder of George Floyd, violence against people from different racial, ethnic, religious and gender minorities and the glaring health disparities laid bare by COVID-19 cast a much-needed spotlight on the effects of systemic racism and bias on the health and well-being of Black, indigenous and people of color and other traditionally marginalized groups.

Diversity, equity and inclusion are core organizational values that provide us with a path for improving health outcomes for all members of our community. We spent 2020 exploring ways to build these core values into all of our operations and programs. The events of the past year compelled us to look inward and focus more of our resources on what we can do right now—and how we can build on these efforts to continue our progress for our future. We have a long way to go, and we will share our efforts throughout the coming year.

We recognized that reaching all members of our diverse community involves efforts from both inside AND outside our organization. Rather than attempting to be all things to all people, we are prioritizing working with existing groups that are focused on reaching marginalized populations and addressing health disparities. Our partnership program will help bring resources to all members of our community.

We prioritized improving health equity through our health literacy efforts. The government's "Healthy People 2030" action plan added a new definition to health literacy. "Organizational health literacy" describes the degree to which organizations equitably enable individuals to find, understand and use information and services to inform health-related decisions and actions for themselves and others. FORCE is focusing efforts on improving our health literacy by training staff, volunteers and healthcare professionals on the importance of using plain language and consistency in communications with patients.

We are working to ensure the inclusion of people of color, those in the LGBTQ community, the disabled and other underserved communities in leadership positions within the organization, including our board of directors and Scientific Advisory Board.

We have completed our first XRAY article in Spanish on COVID-19 and cancer and are working with our partners to select additional XRAY articles to be translated into Spanish.

We have begun an accessibility audit for our website and all digital communication. We are engaging American Sign Language translators and interpreters for support meetings, when needed.

With the launch of more virtual support meetings, **we are now able to create meetings that are specific to unique communities within our organization.**

We are continuing to focus on policy efforts that aim to reduce disparities in access to care, including genetic testing and screening.

Education

A global pandemic, an expanded mission, a complete website redesign with new content and a cancelled conference all converged to make 2020 a daunting year for our education team. Up for the challenge, in 2020 we accomplished the following milestones:

As part of our website and mission expansion, **we added expert-reviewed information and resources on the genes and cancers that are associated with Lynch syndrome**—the most common inherited cancer syndrome—to all of our educational content.

We've continued to add personalized portals on our website to help people find information that is tailored to their concerns, including: living with increased risk, endometrial cancer, colorectal cancer, biomarker testing, Lynch syndrome, menopause management and information for healthcare providers.

In response to the crisis of the global pandemic, **we quickly developed website content that was focused on expert-reviewed, reliable information on COVID-19** and the disruption to screening, preventing and treating hereditary cancer. This information was accompanied by a COVID-19 webinar series, which included seven live and on-demand presentations with experts who addressed common concerns and misperceptions related to COVID-19 and cancer.

"Our community is often bombarded with media coverage related to hereditary cancer risk and susceptibility. Without guidance, it can be hard to separate facts from misinformation. XRAY helps improve people's health literacy and empowers them to make informed medical decisions."

MARCELA GAITÁN

Program Director of FORCE partner, Nuestras Voces (Our Voices) Network



Our XRAY program looks behind media headlines to provide plain summaries about cancer research and how the science does or does not affect medical care. Initially developed through a CDC grant focused on breast cancer, we expanded XRAY to provide reviews of research that are related to ovarian, prostate, pancreatic and, most recently, colorectal and endometrial cancers. **We reached a milestone in June, publishing our 200th XRAY review.** To reach a wider, more diverse audience, we are beginning to translate XRAY reviews into Spanish and enhance select reviews with video animations.

At the end of 2019, we were awarded a CDC grant for Project EXTRA to help improve health outcomes for young breast cancer survivors and people living with metastatic breast cancer. This grant focuses on improving provider/patient communication and addressing health disparities. In 2020, as part of this effort in collaboration with our Project EXTRA Partners, **we developed a workshop for healthcare providers, public health professionals and community health workers who are focused on addressing health disparities and improving health literacy.** This includes a series of tools and resources to help these professionals communicate clearly and in plain language. We also conducted training for our FORCE volunteers and oncology nurse navigators.

FORCE participated in the Consistent Testing Terminology Working Group (CTTWG), a large collaborative consortium of over 40 nonprofits, industry organizations and professional societies working toward improving patient understanding by standardizing the terms that organizations use to describe genetic and tumor test results in patient-facing materials. **FORCE helped lead a large, national patient survey that concluded that patients are unfamiliar with many terms that are used to describe tumor and genetic testing.** The survey indicated that patients prefer the terms “genetic testing for inherited cancer risk” and “genetic testing for an inherited mutation.” The results of this effort were published in a [white paper](#) that has been shared through members of the working group, including FORCE.

By the numbers:

475,000

visitors to the hereditary cancer information library portion of the website

126,000

visitors to our XRAY program

42,000

visitors to the information portals

3,500

people viewed our webinars


Advocacy & Public Policy

2020 brought challenges and change to the public policy landscape. FORCE rose to the occasion as the COVID-19 pandemic and ongoing political divisiveness significantly influenced our community and our work. With our growing community in mind, we strengthened and expanded our partnerships with other nonprofits and healthcare professional organizations.

We also collaborated in coalitions to ensure that the interests and needs of people with or at risk of hereditary cancer were represented.

Our work included:


- Successfully advocating for approval of COVID relief packages, including 90-day supplies of medication, expanded patient assistance programs, expansion of telemedicine and more.
- Engaging in state legislative efforts to improve access to genetic counselors and affordable high-risk breast screenings.
- Spearheading initiatives to improve access to genetic counseling, testing, increased screening and risk-reducing interventions for Medicare beneficiaries.
- Representing the hereditary cancer patient community in efforts to reform federal regulation of laboratory-developed and in vitro diagnostic tests.
- Continuing efforts to improve labeling, communication and rupture screening guidelines for those who have had breast reconstruction with implants.
- Fighting to maintain existing patent law provisions, including the 2013 AMP v. Myriad Supreme Court ruling that naturally occurring DNA sequences cannot be patented.
- Advocating for Florida's enactment of the most comprehensive genetic protection law in the U.S. that protects genetic information from life, long-term care and disability insurers, which are exempt from the national protections provided by the Genetic Information Nondiscrimination Act (GINA).
- Persisting in efforts to achieve parity on oral chemotherapy coverage, continued access to mammograms for the general population beginning at age 40 and fighting policies that would compromise genetic information and protections in employee wellness programs.
- Influencing Blue Cross Blue Shield to revise its Federal Employee Plan policy documents to reflect coverage of risk-reducing surgeries for high-risk individuals.
- Making significant revisions and additions to the legal, policy and insurance coverage sections of the FORCE website to better meet the needs of our community.



“We received a notice from our insurance that based on all the information we submitted they have changed the policy and now allow the prophylactic mastectomy for women with BRCA mutations...we just wanted to let you know that your hard work is paying off!

Both you and your organization have been an amazing source of encouragement, strength and leadership on what we need to do to make change happen! So, we will keep pushing forward! Thanks again for all your support along the way.”

STEPHEN AND YARELA OSGOOD



“Blue Cross Blue Shield finally approved my prophylactic mastectomy (that they initially approved, then denied). I downloaded and sent appeal letters from the FORCE website, and that’s what did it! I have a PALB2 mutation, not BRCA—which I think was part of the problem—and they have sample appeal documents for this! I definitely recommend FORCE as a resource.”

SUSAN KARNICK
PALB2 & ATM Previvor

Support

During this challenging pandemic year, 384 dedicated volunteers helped us to quickly pivot to support our community and address their physical and emotional challenges with virtual services and COVID-19-related webinars and resources.

Volunteers provided hope and a safe space for others to share and express their concerns about cancelled screenings, surgeries and treatment via our online message boards, virtual Zoom support meetings, Peer Navigation and helpline calls. Changing from in-person to virtual support increased access to individuals who live in rural and remote communities, ensuring that no one faces hereditary cancer alone.



384 volunteers

supported and advocated for our growing community

729 individuals

received personalized peer navigation support

250 people

spoke with helpline volunteers

3,933 posts

were shared on our message boards

897 attendees

participated in 127 support meetings

2,682 participants

viewed 12 educational or COVID-19 webinars



We relaunched our VolunteerFORCE Academy with a 15-course, online curriculum to train volunteers on our newly expanded mission to support and advocate for our growing community. The new interactive training includes videos, quizzes and real-life situations that empower volunteers to share factual information without advice or judgment.

“I was thrilled to see that FORCE offers a program where I could talk to other people who carry the same mutation as me. It was so comforting to speak with women who went through what I was going through and to see that they were doing just fine.”

CINDY TOWNSEND
ATM Previvor



“I joined the FORCE community to reach out to men with genetic mutations and hereditary cancer. We need more men to engage in our community, because half of all people with inherited mutations are men.”

DOUG MURRAY
BRCA1 Pancreatic Cancer Survivor



Research

We continue to accelerate research that is focused on hereditary cancer by educating our community about clinical trials and matching qualifying community members to hereditary cancer detection, prevention and treatment studies.

We enhanced the Search and EnrollTool and Featured Research for the new website to include new cancers (colorectal and endometrial), new genes and new biomarkers. We assisted with enrollment for over 60 clinical trials, resulting in 63,000 visitors to our research and clinical trials sections.

In 2020, we had 95 trained research advocates who were placed in 67 opportunities and served in a variety of roles, advising on studies and other cancer-related efforts to provide meaningful input into the design and conducting of research to help assure that the studies are most responsive to our community's needs.



“The training I received through FORCE’s Research Advocate Training gave me the knowledge to confidently participate in and pursue those research opportunities that make a difference to the hereditary cancer community and prepared me to vigorously advocate for those of us with a genetic predisposition to cancer.”

CARMEN R. PACE
BRCA2 Breast Cancer Survivor



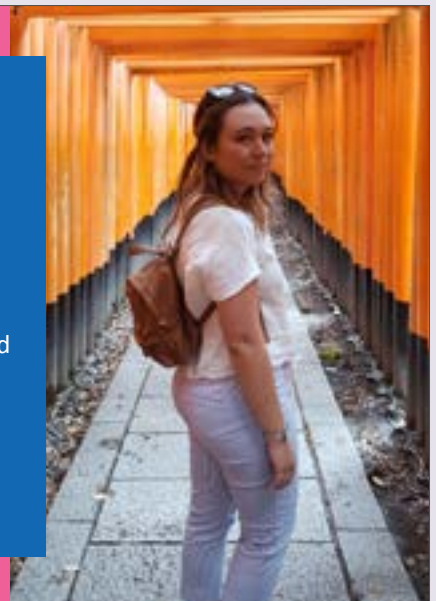
Research Advocate Participation 2020:

Alamo Breast Cancer Foundation
AliveandKickn
Alliance for Clinical Trials in Oncology
American Association for Cancer Research
American Society of Clinical Oncology
American Society for Gastrointestinal Endoscopy
AstraZeneca
Basser Center for BRCA
BRCA Data Commons
California Breast Cancer Research Program
California Comprehensive Cancer Control Program
Centers for Disease Control and Prevention
Conquer Cancer: The ASCO Foundation
Dana-Farber Cancer Institute
Department of Defense Congressionally Directed
 Medical Research Programs
Duke Cancer Institute
ECRI Institute
Emory University
ESCAPE to Thrive
Food and Drug Administration
Georgetown-Lombardi Comprehensive Cancer Center
Harvard University
Huntsman Cancer Institute
International Gynecologic Cancer Society
Living Beyond Breast Cancer
Michigan Cancer Consortium

Michigan Department of Health and Human Services
Moffit Cancer Center
National Cancer Institute
National Cancer Institute Genomic Data Commons
National Coalition for Cancer Survivorship
Novartis Oncology
NRG Oncology
Oregon Health & Science University
Patient-Centered Outcomes Research Institute
Personalized Medicine Coalition
Research Advocacy Network
San Antonio Breast Cancer Symposium
Society for Integrative Oncology
Society of Nuclear Medicine and Medical Imaging
Susan G. Komen
TESARO
The American College of Obstetrics and Gynecologists
The Cancer Forums
The National Patient-Centered Clinical
 Research Network
Tigerlily Foundation
Translational Breast Cancer Research Consortium
University of Chicago
University of Pittsburgh Hillman Cancer Center
University of South Florida
Washington Department of Health

“FORCE’s Research Advocate Training (FRAT) Program prepared me by teaching the science and biology behind hereditary cancers, the current status of research, as well as how advocacy works. Even though I have a science background, this program really helped me understand more nuanced topics, such as clinical trials and genetic testing. I feel prepared to advocate on behalf of the hereditary cancer community and FORCE.”

CARISSA MIYANO
BRCA2 Previvor



Awareness

This past year was about sharing the boldness, diversity and hope of our expanded community so that we could attract, educate and support even more people with various inherited gene mutations and cancers.

We did that primarily through an extensive outreach campaign that was driven largely by personal stories, proving that while we all have different cancers, mutations and challenges, we are a single FORCE community and we share a common bond. Whatever your hereditary cancer mutation or diagnosis, FORCE is here for you.



Our new motto says it best:

**Many Mutations.
Many Cancers.
*One Community.***



FORCE renamed National Hereditary Breast & Ovarian Cancer Week to the broader, more inclusive National Hereditary Cancer Week.

This change reflects the growth in genetic research and FORCE's move to support populations of many inherited mutations and cancers. September 27 – October 3, 2020 was the inaugural National Hereditary Cancer Week, allowing us to honor ALL people affected by hereditary cancer.

Our Supporters

FORCE wishes to thank the individuals, foundations and corporations that have generously supported our mission in 2020.

\$100,000 and above

Anonymous to honor Sherry Pedersen
AstraZeneca

\$50,000 – \$99,999

Anonymous
David Nixon
Eisai
Genentech
TELETIES LLC
The Allergan Foundation

\$25,000 – \$49,999

Clovis Oncology
GlaxoSmithKline
Merck
Myriad Genetics, Inc.
Novartis
Pfizer Inc.
Saul and Theresa Esman Foundation

\$10,000 – \$24,999

AbbVie
Bristol-Myers Squibb Company
Constance M. Chen, MD
Daiichi Sankyo, Inc.
Hologic
Maralee Schwartz
Mary Stranahan Foti and Anthony Foti
Tammy and John Li

\$5,000 - \$9,999

Basser (University of Pennsylvania)
Brighton Retail
Brown-Carrigan Family
Cancer Treatment Centers of America
Eva Bryer and Bardia Pezeshki
Foundation Medicine
Jan and Paul Gronemeyer
Jeffrey Zindel
Joshua Levine
LabCorp
Patty Dodson
Quest Diagnostics
Rebecca Sutphen
Robert & Rose Glick Charitable Foundation
Textron Matching Gift Program
The Cole Family

\$1,000 - \$4,999

AmazonSmile
Annette and Robert Seelig
Anonymous
Association of Community Cancer Centers
Baltimore Community Foundation
Bill and Eva Roche
Brad Starr
Cancer Support Community
Cari Roth and Wellington Meffert
Carrie Catlin and Steve Wintermeier
Christina and Tim Cohen
David and Amy Dessert
Diane and Thomas Rose
Donelan Giving Fund
Elaine and John Kennedy
Ellyn Davidson
Elora Ortego
Evelyn Philipps
HSN LLC
Informed DNA
Jane Schapiro Brown and Scott Brown
Jeff and Sharon Kulik
Jody Gunn
Judy Calabria
Kristine Schannauer
Laura Mlynarczyk
Leslie Rose
Linda Grier
Magee Women's Hospital
Margaret Stewart and Severin Borenstein
Megan LoPresto
Michael Rogan
Michelle and Jonathan Barsook
Myles Brown and Judy Garber
National Comprehensive Cancer Network, Inc.
Patricia Stahl
Petersen's House of Carpets
Rebecca and Kenneth Carr
Richard and Marilyn Kossik
Robin Karlin
Sandy and Barry Cohen
Sommer Family Charitable Fund
Stephen and Janet Groft
Sterling Management Corp.
Steven Davis
Tami Diehm
Tankenoff Families Foundation
Tara Freundlich
Teri* and Duncan Woodhull
Jodye and Peter Glicke
Theobald Chandler Family Giving Fund
William Stewart
YourCause, LLC

*Deceased

Legacy Circle

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.

Anonymous

Dave* and Jessie Bushman

Rebecca and Ken Carr

Sandy and Barry Cohen

Joel Hostetter*

Karen and Steve Kramer

Tammy and John Li

David Patrick Nixon

Sandi and Bruce Ogin

Barbara and Alan Pfeiffer

Michael Sosin and Tedi Siminowsky

Teri* and Duncan Woodhull

Members of the FORCE Legacy Circle will help strengthen the organization for years to come and help provide stability as we plan for the future.

FORCE supporters interested in joining the FORCE Legacy Circle or desiring more information may contact Rebekah Wells, Major Gifts Officer at rebekahw@facingourrisk.org or (866) 288-7475 ext. 715.



Lifetime Giving Society

This past year, FORCE established the Lifetime Giving Society and honored three inaugural members. This group of individuals and family foundations have given generously to FORCE, each cumulatively donating more than \$100,000 to the organization.

We invite you to join us in expressing gratitude for the generosity of these donors. You can read their stories on our website at www.facingourrisk.org/donate/lifetime-giving-society. As FORCE continues to grow, we anticipate this society will add new members who are equally committed to serving the hereditary cancer community.



Michael Sosin

*Thank you for giving
time and time again!*



Maralee Schwartz



The Saul & Theresa Esman Foundation

TeamFORCE

In a year when plans were cancelled, events pivoted to virtual and we faced a ton of waiting and unknown circumstances, we greatly appreciate those who stayed with us through it all and continued their commitment to support our mission. You proved to be unstoppable, raising over \$96,000 through events that, in some cases, did not take place, at least not as planned.

We have many of our 2020 TeamFORCE heroes to thank, such as the superstars highlighted below:



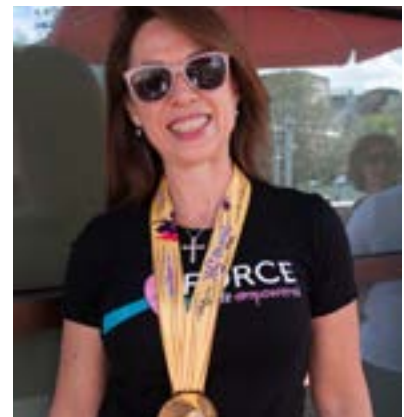
Jan Gronemeyer

Jan is a TeamFORCE Team Leader driving participation in our events and is responsible for our involvement in the TCS New York City Marathon starting in 2020.



Carly Miller

Carly Miller raised over \$7,000 in memory of her mother through her epic swims!



Debbie Denardi

Debbie Denardi is a fundraising champion who participated in multiple events in 2020 to support the mission of FORCE!

TeamFORCE continued through 2020 with events like socially distanced yoga and virtual Zumba, with everyone pulling together to make the best of the circumstances we faced. With patience and understanding, members worked through cancellations and transitions and did not stop their impactful efforts of support. They continued to make a meaningful difference, and we thank them for standing by us in such an “eventful” year.

Besides fundraising tied to events, we had champions who continued their fundraising campaigns via our annual campaign, Facebook and Instagram (added in 2020). Even in the troubling year we endured, this army of individuals and their “friends asking friends” efforts, raised over \$54,000.

Our Board of Directors



Carrie Catlin
President



Tara Freundlich
Vice President



Carmen R. Pace
Secretary



Debora Denardi
Treasurer



Denise
Bulpitt



Ellyn
Davidson



Sue
Friedman



Dana
Goldman



Wenora
Johnson



Elaine
Kennedy



Tammy
Li

Judy Garber, MD
Director Emeritus

Allison W. Kurian, MD
Director Emeritus

David Nixon
Director Emeritus

Rebecca Sutphen, MD
Director Emeritus

“My philosophy is that although I did not choose to be on this HBOC journey, I can choose HOW I travel it. I refuse to live in fear of the ‘what-ifs’ and choose, instead, to live with joy and appreciation, and part of that appreciation is choosing to be an active part of this inspiring FORCE community!”

TERI WOODHULL



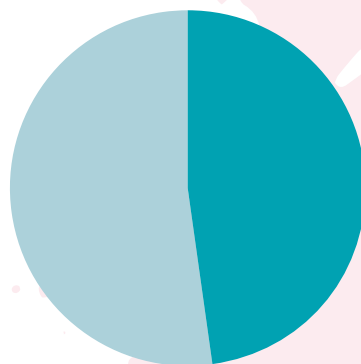
On January 10, 2021, the FORCE community lost a tireless volunteer, an enthusiastic leader, a dedicated advocate, a patient and a dear friend. Teri Woodhull, our Board President, passed away after a decade-long battle with ovarian cancer. Teri was an indomitable part of FORCE over the past 10 years, and she leaves a lasting legacy on our organization.

Financials

In 2020, FORCE spent more than \$1.4 million on programs to support, educate and advocate for the hereditary cancer community.

Revenue and Support

- Contributions: \$1,294,768
 - Grants (Government and Private): \$1,400,409
- Total: \$2,695,177



Expenses

- Programs: \$1,445,344 (80%)
 - Fundraising: \$193,017 (11%)
 - Management and General: \$162,200 (9%)
- Total: \$1,800,561



Net Assets beginning of year: \$1,206,381
Net Assets end of year: \$2,100,997
Change in Net Assets: \$894,616

FORCE

Facing Hereditary Cancer EMPOWERED

FacingOurRisk.org
info@FacingOurRisk.org

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