BRCA Research & Cure Alliance

Preventing Cancer

PROTECTING FAMILY

2023 Milestones

www.curebrca.org

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About Us

The BRCA Research & Cure Alliance (CureBRCA) was officially launched in 2022 as a registered Illinois not-for-profit private foundation. The mission is to advance the knowledge, prevention, and treatment of individuals and families who are affected by *BRCA1* and *BRCA2* gene mutations.

There is a history of BRCA related cancers in our family, and we do not want others with BRCA mutations to have to live with the same fears.

- Michael Polsky

2023 Needs Assessment

In early 2023, we embarked on a journey to learn about current efforts to research, treat, and care for male carriers of BRCA gene mutations. We sought input from specialists in urology, genetics, oncology, and epidemiology, as well advocacy experts. We needed to hear from the medical and research community to understand the BRCA ecosystem better, learn about the existing work and understand how we could contribute. We also consulted thought leaders and gathered information from other foundations and notable charities making significant strides for carriers of BRCA gene mutations and those afflicted by BRCA-related cancers.

Four major “problem areas” came to light through our needs assessment. Armed with this information, we deployed our resources to provide support for problems centered around the following unmet need areas:

Research

Unmet Need #1

After numerous conversations with researchers and medical providers, we recognized that more research is needed to understand BRCA1/2 at the molecular level, more knowledge is needed to understand the difference between specific gene variants and how they affect individuals differently.

- We learned that women who carry BRCA gene mutations have specific recommendations and considerable resources for managing their cancer risk, but much less is known or available for men, even though they make up half of all BRCA gene mutation carriers.
- Prevention directives are well established for women but not for men.
- More men with BRCA need to be identified and studied.
- We need to help the men who carry BRCA gene mutations learn about their cancer risk and have opportunities to mitigate their risk and to engage and partner in research opportunities designed to help them and their family members.

BRCA Research & Cure Alliance

Support

In 2023, we initiated an open call for research applications and ultimately funded **$2.3 million**, distributed among five essential research endeavors.

- We believe that the knowledge uncovered by these research projects will be pivotal to advancing our understanding of prostate cancer, prevention and facilitate, interception; most importantly, to bring awareness and hope to the multitude of BRCA gene mutation carriers.
- These research projects collectively include global collaborative studies addressing prevention, multi-institutional prostate cancer screening efforts, and outreach to identify and provide more resources for male carriers of prostate cancer-associated BRCA gene mutations. The funded research projects span 2-3 years and we look forward to following the progress made in the coming year.
- We intend to fund additional research in 2025 after understanding how these inaugural projects progress.

Education

Unmet Need #2

We recognized that when it comes to BRCA, information is power, but information is not always readily available for men who are seeking information about their mutation.

- Information can be hard to find and the prevention directives are sparse, inconsistent, and difficult to find for male carriers of BRCA gene mutations.

- Doctors and medical providers need a point of reference that clearly identifies the risks and management guidelines, that are accepted by the BRCA Community.

Support

In 2023, CureBRCA spearheaded the concept and creation of a medical white paper that presents the cancer risks associated with *BRCA1* and *BRCA2* gene mutations in men and presents the available data in one centralized place with expert consideration of the context and assembling the recommendations for management.

- It is our hope that this resource can become a universal guide and global resource that all members of the medical community can access freely, and that would provide medical professionals and BRCA gene mutation carriers with information that could help reduce the burden of cancer and save lives.

- The white paper is being prepared for submission to major medical journals, with 19 co-authors and contributors from different institutions across the globe. We hope to report this white paper's publication in 2024.

- We also want to connect male carriers of BRCA gene mutations to reputable resources that further their knowledge of the risks of BRCA gene mutations, prevention, support groups, access to clinical trials, and advocacy. To be efficient, we must not duplicate the efforts of other impactful charities or experts. We want to add to their efforts and help fill the gaps in currently unsupported areas by operating as an access point for information seekers, connecting them to indisputable information to make important life decisions. We have started doing this on our website and are accomplishing this one-on-one as inquiries arrive, directing individuals and families to the best resources tailored to their needs.

Collaboration

Unmet Need #3

We recognized that ground-breaking work is already happening within the BRCA medical community, but much of this work is occurring in silos and more collaboration across institutions not traversing across institutions. For a cause so much larger than any one institution, we need the collective effort of many; we need to work together.

Support

In 2023, we hosted the CureBRCA Collaborative, facilitating dialogue, connection, and information-sharing between researchers, academics, and healthcare providers from multiple institutions. We aim to create a community where scientific leaders can connect, expand upon their knowledge and conceive of new ideas and collaborations.

Additionally, in 2024, CureBRCA plans to host a Genetics Implementation Roundtable, which will include other important stakeholders such as large healthcare systems, guideline experts, drug and testing companies, payors, and patient advocates. The aim for this roundtable will be strategizing on ways to help make genetic testing readily available to a greater number of people.

Outreach

Unmet Need #4

BRCA gene mutations impact not just an individual, but also others in their family tree. We are founded on this experience, and extend the urgency of protecting our own family to protecting the BRCA community through improving prevention, early detection, and treatment. To do this, we must promote advocacy of genetic testing, amplify the voices of BRCA carriers, and support legislation to improve the treatment of men with BRCA gene mutations.

Support

In 2023, CureBRCA supported various advocacy efforts, including the Reducing Hereditary Cancer Act, the Access to Genetic Counselor Services Act, and the PSA Screening for HIM ACT, which push for Medicare and private insurance to cover guideline-recommended genetic counseling, testing, cancer screenings, and preventive care. In 2024, we will continue supporting these efforts and aim to intensify outreach by supporting public campaigns encouraging genetic testing.

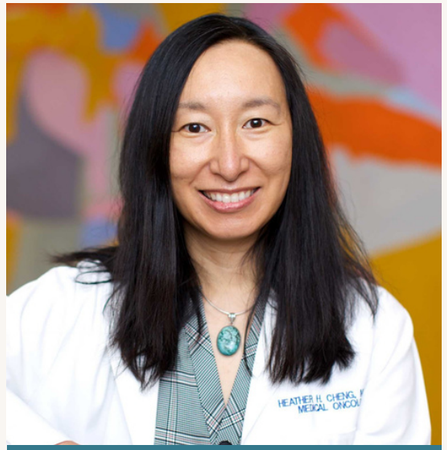
Leadership

Michael Polsky

Founder

Tanya Polsky

Founder



Heather Cheng, MD

Chief Science Officer

Priscilla Kennedy

Managing Director

Thank you

We thank each of you for being an encouraging part of our community and supporting the BRCA Research & Cure Alliance (CureBRCA). We have made tremendous progress in our first full year as a foundation, and we are so grateful to our friends in the medical and research community for their dedication and unwavering commitment to individuals and families affected by BRCA gene mutations. We look forward to partnering with you for another successful year of research, education, collaboration, and outreach efforts.

CONTACT

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