

# Our Impact

JANUARY – JUNE 2021

Since our community expansion at the end of 2020, we have continued to grow. We now ensure that the millions of individuals and families facing hereditary cancer have access to credible information, compassionate support and high-quality programs. We have embarked on a BIG mission to expand our community and ensure that no one with hereditary cancer faces their experiences alone.

Read on to learn about some of the many things we have accomplished over the last six months on behalf of our growing community.

## EDUCATION AND AWARENESS

- Our “Men Have Mutations Too” campaign celebrated Men’s Health Week 2021 by reinforcing the message that men can inherit genetic mutations that put them at greater risk for certain cancers. They can also pass these mutations to their children, reinforcing the generational nature of hereditary cancer and the importance of knowing genetic status so that informed medical decisions, for the entire family, can be made.
- Together with Eisai, Black Health Matters and SHARE Cancer Support, we launched the year-long [Spot Her](#) campaign, an initiative that empowers women to help spot the signs of endometrial cancer, one of the two most common cancers in those with Lynch syndrome. This effort is not only educating, but inspiring women to listen, advocate and put their health first.



“For the first few years I knew I had a BRCA2 mutation, I learned what I could, but only when I found FORCE did I feel I had a real resource for knowledge and support. It is by far the best website on the issue, and the people that I’ve interacted with have been top-notch. I’m currently enrolled in an NIH trial for prostate cancer that was recommended to me by my FORCE peer navigator.”

—Brad Hertz, BRCA2 Previsor

## SUPPORT

- To address many of the issues and challenges that people in our community face in understanding online health information, we created a new volunteer training curriculum consisting of two courses “Health Literacy, Social Determinants of Health and the Impact on Health Outcomes” and “How XRAY Unconfuses Cancer Research Reported by the Media.”
- An expanded team of 344 dedicated FORCE volunteers with diverse experiences, different inherited mutations and hereditary cancers provide support, comforting words and empowering knowledge in a safe virtual environment ensuring no one faces hereditary cancer alone.

## RESEARCH

- Incorporating patient input into the design of research studies can assure that the studies are relevant and responsive to patient needs. We developed a [toolkit](#) to guide researchers on how to work with patients and advocacy groups to incorporate the patient voice and perspective into the design of their research studies.
- We had over 25,000 people view the studies on our Featured Research page. Over 1,200 visitors used our Search and Enroll Tool to find studies.

“ Thank you so much for sharing the vaccine trial info for triple negative breast cancer. I’m crying from happiness and hoping it works now. ”

–XRAY reader

## PUBLIC POLICY

- Advocated for the U.S. Preventive Services Task FORCE to better meet the needs of the hereditary cancer community by improving guidance on identifying men and women who may be at increased risk of colorectal cancer in its new screening recommendations, and to develop Lynch syndrome screening guidelines to help primary care providers screen patients to determine who may be at increased risk of hereditary colorectal and related cancers.
- FORCE is representing the unique needs of Medicare beneficiaries who may be affected by hereditary cancer by spearheading the *Reducing Hereditary Cancer Act*. Medicare covers genetic testing only for beneficiaries already diagnosed with cancer. If someone without cancer learns they have a mutation prior to Medicare eligibility, or they pay out of pocket for genetic testing and find that they carry a mutation while on Medicare, coverage of many medically necessary high-risk cancer screenings or risk-reducing surgeries is legally prohibited. This legislation will modify Medicare statutes to increase access to these medical services.



Facing Hereditary Cancer EMPOWERED

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