

Our Impact

JANUARY—JUNE 2020

The first half of 2020 has been one of the most challenging times in recent history. Due to the COVID-19 pandemic, our country, our communities and each of us individually have had to adapt to frightening and challenging circumstances. We have all had to work hard to create a new sense of normal as things changed rapidly with little notice. Canceling our Joining FORCES conference was crushing, but with that decision came the opportunity to rethink many of our support and educational programs.

FORCE has worked hard these last few months to meet the changing needs of those requiring hereditary cancer resources. Read on to learn about these and other milestones. With everything in our power, we will continue to do our best for you, our valued constituents.

RESEARCH

1. For the first time, the FDA has approved a class of drugs known as PARP inhibitors to treat an aggressive type of metastatic prostate cancer that is common in men with BRCA and other mutations. FORCE helped match patients to the studies that led to these important approvals, helping to provide another treatment option to a subset of men with hereditary prostate cancer.

PUBLIC POLICY

1. In 2018, Medicare implemented a national policy that essentially halted hereditary cancer genetic testing for its beneficiaries. Early this year, we successfully spearheaded efforts to change this restrictive policy, allowing local Medicare regions to cover testing for hereditary cancer mutations and providing greater access for people with cancer.
2. Supported legislation and policies aimed at easing the burden of the COVID-19 crisis on members of the hereditary cancer community, including expansion of medical services for Medicaid enrollees, funding to assure that stalled research resumes, access to 90 days of medications and home anticancer therapies, financial assistance for nonprofits serving the community and more.



“I emailed you for help back on February 14th after being referred by The Sister Study. I needed help finding a genetic counselor. You responded so quickly and supplied me with resources. I met with a local counselor who you helped me find and she was amazing. Unfortunately, I tested positive for a CHEK2 mutation. I went back on the NSGC website and found genetic counselors for my three adult children in three different states. They all have upcoming appointments.

When I contacted you in February, I was very frustrated and frightened. I cannot say enough about how much help I received. From then on it was smooth sailing. Thank you so much. You can't know how much your response meant to me that day.”

—Elise, FORCE Constituent

EDUCATION AND AWARENESS

1. Published our 200th XRAY review (eXamining the Relevance of Articles for You), building on our program to help people better understand news media articles about breast, ovarian, prostate and pancreatic cancer and to educate healthcare providers on how to communicate with their patients about these articles.
2. Piloted our first continuing education opportunity at the Association for Oncology Nurse Navigators' virtual midwinter conference in collaboration with partners at the University of Southern Florida. This marks our commitment to enhancing patient and provider communication about hereditary cancer information.
3. Published our first Spanish language translation of an XRAY review on COVID-19 and cancer. This is one of several efforts to expand accessibility of our cancer education materials to a larger portion of the Hispanic community.

SUPPORT

1. Created a dedicated COVID-19 resource webpage specifically for people affected by hereditary cancers. Organized five expert webinars and partnered on two others to address the physical and emotional challenges of COVID-19 facing our community. Topics addressed concerns about canceled doctor appointments, delayed screenings, treatment changes, how to support loved ones in treatment while practicing social distancing and fears about immune suppression.
2. Piloted a series of virtual support group meetings to replace our in-person gatherings to keep our community safe during the pandemic. We will continue to roll out this successful program across the country.



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