FACING OUR RISK OF CANCER EMPOWERED (FORCE)

United States of America

GLOBAL OVARIAN CANCER CHARTER
a World Ovarian Cancer Coalition initiative

"As an organization in the United States that works to improve the lives of individuals and families affected by hereditary cancers, FORCE is pleased to be a Champion of the Global Ovarian Cancer Charter as we work towards helping women understand and manage their risk, evaluate their treatment options, and gain information, resources and support as they navigate hereditary ovarian cancer. "

FORCE
Facing Our Risk of Cancer Empowered
www.facingourrisk.org

CHARTER CHAMPION

INFORMATION & SUPPORT

Peer Navigation Program

www.facingourrisk.org

CHAMPION PROJECT:
PEER NAVIGATION PROGRAM

Individuals and families who have just learnt they are at risk of hereditary cancers (including but not limited to ovarian cancer) have many questions and issues to consider. FORCE's Peer Navigation Program connects them to cancer survivors, previvors, and other people living at high risk who share the same genetic mutation and circumstances. This means the person they speak with "gets" the situation they are in, having faced it themselves. Program users and FORCE volunteers include not only those with BRCA1 and BRCA2 mutations, but also people with mutations in ATM, BRIP1, CHEK2, PALB2, RAD51C, RAD51D and the genes linked to Lynch syndrome (EPCAM, MLH1, MSH2, MSH6 and PMS2).

Peer navigators do not provide medical advice, but they are trained to empower those who need support and information. Navigators spend between 2-3 hours by phone or email with each person as required. They have vital information and a companion guide that is personalised to the person requesting help.

Individuals can select from over thirty modules on topics related to genetic testing, cancer risk, screening and prevention options, treatment, legal protections, paying for care and sharing genetic information with their relatives. Specific modules also focus on precision medicine, such as biomarkers, immunotherapies and targeted therapies. Quality-of-life modules provide information on survivorship, fertility preservation, menopause management, dealing with treatment side effects, nutrition, exercise, lifestyle, and emotional health and wellbeing. Each program user receives information and assistance according to their unique needs.

Participants may also request clinical trial navigation, which will direct them to studies that are enrolling people with specific inherited gene mutations.

Since its start in 2016, FORCE's Peer Navigation Program has helped over 3,500 people from all over the U.S., Canada and Puerto Rico to deal with living with an inherited gene mutation linked to cancer.

www.facingourrisk.org

The Coalition chose to showcase this programme because it connects people with the same genetic mutation, ensuring that program participants get personalised information that meets their specific needs from someone who shares a common experience. The information is not limited to BRCA mutations, nor is it all clinically based, building on the incredible expertise of FORCE in navigating the legal and insurance aspects of genetic testing and treatments.

GLOBAL OVARIAN CANCER CHARTER
a World Ovarian Cancer Coalition initiative

FACING OUR RISK OF CANCER EMPOWERED (FORCE)

United States of America

GLOBAL OVARIAN CANCER CHARTER
a World Ovarian Cancer Coalition initiative

"As an organization in the United States that works to improve the lives of individuals and families affected by hereditary cancers, FORCE is pleased to be a Champion of the Global Ovarian Cancer Charter as we work towards helping women understand and manage their risk, evaluate their treatment options, and gain information, resources and support as they navigate hereditary ovarian cancer. "

FORCE
Facing Our Risk of Cancer Empowered
www.facingourrisk.org

CHARTER CHAMPION

FAMILY HISTORY

Advocacy Program

www.facingourrisk.org

CHAMPION PROJECT: ADVOCACY PROGRAM

Advocating on behalf of those with hereditary cancers, with a focus on improving their outcomes is a top priority for FORCE. Within the complex healthcare setting of the United States, federal and state laws, regulations and guidelines affect the health information and care that people receive.

FORCE has been involved in leading efforts and collaborations with other organizations to enact or improve laws, policies and regulatory oversight that increase access to healthcare and provide better protections for members of the hereditary cancer community. FORCE tracks legislation and trains and mobilizes their constituents to share their experiences and raise their voices to influence public policy.

Over the years, FORCE has been involved in key developments, including passage of the Genetic Information Nondiscrimination Act (GINA) and efforts that led to the Supreme Court overruling gene patents. Most recently the organization 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 cancer risk. FORCE also advocated to expand Medicaid coverage of BRCA genetic testing, which is now covered in 47 of 50 states. In addition, they uncovered and reported genetic test scams to federal agencies, leading to charges against individuals for fraudulent genetic testing and billing practices.

FORCE's current priority list includes introducing legislation to require Medicare to cover BRCA testing, assuring passage of legislation that allows genetic counsellors to bill for services under Medicare, and expanding GINA protections against genetic discrimination to include life, long-term care and disability insurance. These have been exempt from protections provided by the Genetic Information Nondiscrimination Act (GINA).

The Coalition chose to showcase this programme because FORCE has developed an extraordinary expertise in an extremely complicated area. The organization has been able to successfully influence outcomes by sharing the stories of those affected by hereditary cancer and challenging guidelines, policies and laws that would negatively affect those families with a hereditary cancer link.

www.facingourrisk.org

GLOBAL OVARIAN CANCER CHARTER
a World Ovarian Cancer Coalition initiative