



THE *BRCA* FOUNDER OUTREACH STUDY

The *BRCA* Founder Outreach (BFOR) Study is an innovative research initiative that will use an online platform and other novel approaches to health care delivery to address a longstanding, unmet need: access to screening for *BRCA* mutations. It has significant potential to save lives and advance progress in the emerging field of precision medicine.

SAVING LIVES

Both women and men with a *BRCA* gene mutation have a significantly heightened risk of developing a range of cancers, including breast, ovarian, and prostate cancer. Yet, until now, testing has largely been limited to those with a family history of these cancers, which does not capture up to 55 percent of individuals with the mutation. As a result, an estimated 90 percent of *BRCA* carriers do not know that they are *BRCA*-positive.

BFOR seeks to make life-saving knowledge of *BRCA* mutations more accessible to a greater number of people in a uniquely sustainable, scalable, and responsible way. It will provide those who test positive for a *BRCA* mutation with information to take steps that can significantly reduce their risk—and with the ability to share this knowledge with relatives who also have an increased likelihood of carrying a mutation.

A NEW MODEL FOR GENETIC TESTING

BFOR will assess the effectiveness of a new model for genetic testing, which incorporates a state-of-the-art online platform and an unprecedented partnership with primary care providers.

Study participants will confirm their eligibility and register using an online platform,

complete an online education module, provide their informed consent electronically, and supply a DNA sample at a lab in their community. The participant's primary care physician or a BFOR cancer genetics specialist will provide test results and follow-up genetic counseling if appropriate. All personal data will be secured and protected at the highest professional standards, in full compliance with HIPAA and state and federal law.

This online platform makes the testing process more easily accessible for the public, expands the number of individuals who can be tested, and make the most effective use of genetic counseling services for those in need of individualized guidance. At the same time, BFOR's unique study design will identify best practices for incorporating primary care providers as partners in the genetic testing process. This will help to support the use of personalized genetics as a clinical tool in the realm of everyday medical care.

A NEW FRONTIER IN MEDICINE

BFOR will inform how our health care system can better integrate genetic testing to optimize and personalize medical care for all populations. Understanding genetic markers can help patients recognize their risks and make more informed lifestyle choices, enabling more effective prevention and treatment of cancer and many other

diseases, such as diabetes and cardiovascular conditions—now and in the future.

ENGAGING INDIVIDUALS OF ASHKENAZI JEWISH ANCESTRY

At this point in the evolution of precision medicine, there is a strong scientific rationale for starting population-based testing among those of Ashkenazi Jewish ancestry. There are several reasons why leading researchers believe that beginning with a population at increased risk is an effective way to demonstrate and refine a new model for genetic testing.

- Ashkenazi Jews carry *BRCA* founder mutations at a frequency at least *ten times* higher than the rest of the population.
- *BRCA* genetic tests are cost-effective and in those of Ashkenazi ancestry can provide a conclusive *yes* or *no* result.
- Testing can lead to life-saving intervention.

To share this message, BFOR's outreach campaign will seek to educate, inform, and partner with members of the Jewish community representing all denominations and backgrounds. **This year, BFOR plans to begin a pilot study of 4,000 people of Ashkenazi Jewish ancestry—1,000 each in the New York, Boston, Philadelphia, and Los Angeles metropolitan areas.** This study will help direct future plans for a larger national study of those of Ashkenazi Jewish ancestry.

BFOR is an independent research initiative headed by leading experts in the fields of cancer research and genetics.

BFOR EXECUTIVE COMMITTEE

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