WHY FREE THE DATA?

The Challenge

More than half a million women and men in the United States have a mutation in the *BRCA1 or 2* genes, which can significantly increase the likelihood of developing hereditary breast or ovarian cancer. As a result, individuals with mutations face difficult decisions.

In 2013 the United States Supreme Court struck down the patent on *BRCA1/2*, declaring naturally occurring genes to be unpatentable. **But, for therapy to move forward, the known *BRCA1/2* mutations and their clinical significance need to be publically cataloged.** We need this data to improve the medical community's understanding of different mutations' impact on health.

The problem? **The necessary *BRCA1/2* mutation data are *not* openly available.** The largest database of mutations is unavailable to individuals and their clinicians as they try to make important treatment decisions. The database is unavailable to investigators as they try to improve prevention and care. This is unacceptable. It is time for a change. It is time to **Free the Data**!

The Solution

Free the Data is a grassroots movement collecting mutations and sharing them with ClinVar, an open-access database of mutations run by the NIH. By inviting women and men to share their mutations and clinical data in a safe way, with user-specified privacy settings, an open-access resource can be populated to gain a better understanding of hereditary breast and ovarian cancer.

This resource will result in more informative *BRCA1/2* testing, better treatment options for those with *BRCA1/2* mutations, and ultimately, improved human health. Soon the campaign will expand to encompass all genes and all mutations, powering **new research** and **better health for all**.

The Ask

Free the Data asks women and men with *BRCA1/2* mutations to **share their variants** with ClinVar, the open access database of genetic variation from the NIH. We also ask for **clinical information** so researchers can improve our understanding of the mutations' effect on human biology. Participants use tools we provide to set data sharing, privacy and access preferences. This rich data set is living and breathing, allowing the engagement necessary to advance medical research and provide pathways to better care.

Free The Data is the work of a consortium of organizations, managed by Genetic Alliance and supported by the University of California, San Francisco (UCSF), the International Collaboration for Clinical Genomics, Invitae, Private Access, Syapse, and Captricity. Questions? Please visit our site, ***www.Free-the-Data.org****, or contact us at* ***freethedata@geneticalliance.org****.*