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****.*

FREE THE DATA: HOW IT WORKS

What We (And You!) Are Doing with This Data

Free the Data is working to build an open access database of *BRCA1* and *2* mutations and associated clinical data, available to researchers and clinicians working to improve our understanding of hereditary breast and ovarian cancer. What's different about this database, though, is that it's open access on the terms of the person who's sharing. Free the Data does share mutation data with ClinVar, the open access database of genetic variant data at the National Institutes of Health… but access to any other health information you provide through Free the Data is **controlled by you**.

Free the Data uses a different kind of platform: PEER, the Platform for Engaging Everyone Responsibly. PEER is a platform from Free the Data partners Genetic Alliance and Private Access that empowers women and men to **take control of their health** and **drive medical research that matters**, by safely sharing medical test results and answering survey questions . When you create an account with PEER the first thing you do is decide who can and cannot access your health information. This means that the data in PEER is only available to specific researchers, advocacy groups and other health organizations with the permission of the person who shares it.

How to Share Data & Get Involved

Step 1: Create an account at www.Free-the-Data.org/freemydata and choose your personalized privacy settings. You select who can and cannot see and use your anonymous data, and who must ask first! You can change these settings at any time.

Step 2: Upload your deidentified *BRCA* report or hereditary cancer panel. We provide instructions on how to remove identifying information from your report. With your permission, your report will be shared with the open access database of genetic variation, ClinVar.

Step 3: Share additional health information with researchers and other groups of your choice, by answering some questions about your health. You can answer as many or as few questions as you would like. Depending on your personalized privacy settings investigators may want to use this information in a study.

Step 4: Visit www.Free-the-Data.org/join and help us spread the word: genetic information is more valuable when shared!

*Note: If you'd like to opt out of creating an account with Free the Data and just share your report, that's okay too! Simply click on "Upload your BRCA Report" at **www.Free-the-Data.org/freemydata**. If you decide to share your report without creating an account, however, you will not be able to share additional clinical information with researchers or other groups of your choice who are working to improve our understanding of hereditary breast and ovarian cancer.*

For more information on sharing reports, including information about who can share, please visit **www.Free-the-Data.org/learn**.