Join the movement to Free the Data!

Dear _____,

I'd like to tell you about an opportunity to safely share your genetic testing data and health information with researchers working to improve testing and care for hereditary breast and ovarian cancer: the Free the Data registry. Free the Data is a grassroots movement building an open access database of *BRCA* mutations and associated clinical data, that gives you the tools you need to share data on your terms. Read on to find out how you can join the Free the Data movement!

- Visit www.Free-the-Data.org and watch the video to learn more about why we need open access to data about mutations in *BRCA* and other genes.
- Then, make the decision to Free your Data! Visit www.Free-the-Data.org/FreeMyData and follow these simple steps…

  1. Create an account with the Free the Data registry 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.
  2. Upload your deidentified *BRCA* report or hereditary cancer panel. Free the Data provides instructions on how to remove identifying information from your report. With your permission your anonymous testing results will be shared with the open access database of genetic variation, ClinVar.
  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.
  4. Now that you've Freed your Data, visit www.Free-the-Data.org/join and help us spread the word: genetic information is more valuable when shared.

For more information about the Free the Data movement, please contact me with additional questions or visit www.Free-the-Data.org/about. Free the Data is the work of a consortium of organizations, managed by Genetic Alliance and supported by the University of California, San Francisco, the International Collaboration for Clinical Genomics, Invitae, Private Access, Syapse and Captricity.

Signed,

_____