

Gene Talk: What do we Expect from Families and their Doctors?

You are invited to be considered for a research study through Oregon Health & Science University. This study has the potential to improve medical care for the ataxia community.

Gene Talk: What do we expect from Families and their Doctors? is a US national study sponsored and funded by the National Institutes of Health. The purpose of the study is to collect thoughts, opinions, and beliefs from patients and providers about who has responsibility for sharing genetic risk information within families, and when it is morally acceptable not to share information. The investigators believe that the opinions of people who actually live with genetic diseases, are key to their research.

The study is structured to be easily understood. All data is stored and managed by Jennifer Poat, Research Associate at the Oregon Health and Science University and the project manager for *Gene Talk*. If you have any questions regarding this study she welcomes your questions at 503-494-2563 or poatj@ohsu.edu.

The data will be collected through an IRB-approved mailed survey. The survey will present 12 short stories about different ways providers and patients might react to situations that might involve sharing genetic information with family members. Each brief story is followed by 2 questions. The entire survey takes about 15 minutes to complete.

If you would like to participate, as a first step, please go to an online survey to fill out your contact information. Once you have done this, the survey will be mailed to you at the address you provided in the online survey. It is important to note that the researchers will not have access to your email address—the website is set up so that email addresses are not “captured.” All information will remain confidential and names will not be connected to answers.

This is the link to the survey:

https://www.surveymonkey.com/s.aspx?sm=C_2fGj736r_2fLAHxJnp1YMBRQ_3d_3d

Thanks very much for your help!