

RESEARCH SURVEY RECRUITS YOUR RESPONSE

You and your family members are invited to participate in a survey titled:
**Perceptions and Values Regarding DNA Contribution to Genetic Biobanks:
Survey Design, Generation and Testing**

The survey asks about how you value particular factors in DNA contribution for future genetic research. Families living with rare genetic conditions have high stakes in future DNA biobank practices therefore the ataxia community is encouraged to respond to this survey. Eligibility to participate is NOT limited to the diagnosed person. Persons at risk and family members not at risk are invited too.

Your identity will not be submitted with the survey therefore your responses are completely private and anonymous. Please call the nurse scientist conducting the study to leave contact information. The survey will be privately mailed to you and your family. Postage for survey's return is provided.

Your participation provides important information that informs development of safe and fair practices for biobanks that collect and store your DNA for future research.

Call Pamela Williams, JD, MS, RN at toll free number: 866-931-3630