Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA)

Please email research@ataxia.org to request full application

Program Description:

The Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA) enrolls research participants who have a confirmed diagnosis of SCA 1, 2, 3, 6, 7, 8 or 10. There is a need to define natural history in geographically distinct areas and develop additional methods to document progression that may be more sensitive and reliable. There is also limited knowledge of factors that may modify symptoms of SCA.

Program Aims:

1. Longitudinal collection of natural history data from individuals with SCA using:
    i. Established clinical rating scales for ataxia previously validated in a European SCA cohort.
    ii. Novel clinical rating scales for longitudinal validation.
2. Creation of a CSF, plasma, serum, and DNA (whole blood) biorepository matched to high quality clinical data to facilitate the development of biomarkers and advance our understanding of genetic modifiers of disease progression in SCA.
3. Support and advance translational studies through direct collaboration with researchers, including data sharing, biological sample collection and distribution, and consultation on experimental design and implementation.

Core Site Activities:

Each Research Institution shall complete the following core site activities:

1. Schedule subject appointments; new and return. Obtain and maintain all appropriate participant consent forms. Every effort should be made to encourage ongoing participation for participants through annual visits scheduled within a 3-month window of the baseline visit.
2. Coordinator or similar person at Research Institution is expected to spend 10-15 hours per week on CRC-SCA related activities.
3. Subject visits and assessments – at each baseline and annual visit, complete the core set of clinical measures and quality of life assessments including (as authorized) a one-time collection of blood for DNA repository and optional collection of other biospecimens in a manner consistent with the applicable IRB approval.
4. Enter all participant data into the study database and make every effort to resolve queries in a timely manner.
5. New data queries (per invoices) from NAF must be addressed by Research Institution within 3 months of notification.
6. Protocol Amendments must be submitted to local IRB within 3 months of UCLA IRB approval.

Grant Funding:

1. NAF will provide baseline site grant support to each Research Institution annually. This baseline support is primarily intended to support coordinator time for recruitment, retention, data entry, visit organization and implementation and regulatory work. Other potential expenses may include IRB fees and start-up costs.
2. NAF will grant Research Institution Grant Funds for each new or return research participant completing a CRC-SCA visit during the 2022 Project Term.
3. No Grant Funds provided by NAF may be used by Research Institution for indirect/F&A costs.