

Participants Needed for Research in Spinocerebellar Ataxia

CLINICAL TRIAL READINESS FOR SCA1 AND SCA3 -READISCA-

DO YOU MEET THE FOLLOWING STUDY CRITERIA?

- You have the clinical or genetic diagnosis of spinocerebellar ataxia type 1 or type 3 (SCA1 or SCA3) **OR**
- Diagnosis of SCA1 or SCA3 in one of your first degree relatives

For example

- You have early ataxia and your parent has SCA1 or SCA3
- You have no symptoms but you were tested positive for SCA1 or SCA3
- You have no symptoms and have not taken DNA testing, but your sibling tested positive for SCA1 or SCA3

If so, then you may qualify for participating in this international multi-institutional study. Please note that various restrictions may apply for the eligibility.

MAIN GOALS OF THIS STUDY

- To establish the world's largest group of early stage and symptomless SCA1 and SCA3 individuals.
- To validate imaging signs in early stage and symptomless SCA1 and SCA3 individuals.
- To adapt recent findings to design clinical trials for spinocerebellar ataxias.

IRB# Pro00022607

If you are interested and would like to have further information, please contact:

National Ataxia Foundation

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Please note that there are 18 study sites across the US where you can participate in this project

- This is not a treatment trial. Rather, this study is to get ready for treatment trials we anticipate within 5 years.
- This research visit will likely take about half a day. You will be asked to return annually for the next five years.
- We will draw blood and perform DNA testing to confirm your genetic diagnosis, and if you wish to know your gene status, we will release the DNA results to your doctor or genetic counselor at no cost to you.
- You will be asked about optional spinal fluid collection by spinal tap (you can say "no" but the spinal fluid is extremely important for developing new drugs for SCAs).
- If qualified, you will be asked to participate in an imaging study using an MRI machine in Boston, Baltimore, Minneapolis or Gainesville (FL).
- There will be no cost for participation, and all expenses will be paid.

