

Thank you for your contributions to the PROSPAX Surveys!

These surveys aim to collect information from people with all forms of ataxia/HSP to develop an assessment tool for these conditions.

WHAT IS PROSPAX?

The PROSPAX (PROgression chart of SPastic ataXias) project, which focuses on ARSACS and SPG7, is a collaborative effort between neurologists across several sites throughout Europe and Canada. The Ataxia Charlevoix-Saguenay Foundation is one of the 3 organisations participating in this project. The overall aim is to gain a better understanding of how spastic ataxias progress over time. For more information, see <https://arsacs.com/research>.

WHAT INFORMATION ARE WE COLLECTING FROM THE SURVEYS?

SURVEY 01

- Assessed frequency of potential symptoms of ataxia/HSP
- Used to produce a shorter list of symptoms for Survey 2

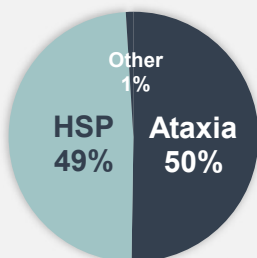
SURVEY 02

- Assessed severity and impact of potential symptoms
- Currently using the data to produce an assessment tool**

ASSESSMENT TOOL

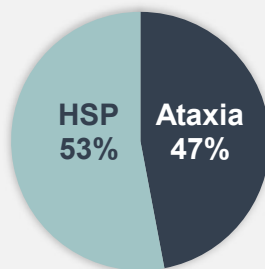
- Will be a 15-20 item questionnaire
- Can be used to measure changes in a person with ataxia/HSP's health over time and the effect of potential new treatments in clinical trials

1125 RESPONSES FOR SURVEY 1



Number of respondents with ARSACS
69 for Survey 1

817 RESPONSES FOR SURVEY 2



83 for Survey 2

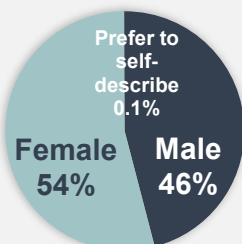
SURVEYS TRANSLATED INTO 6 LANGUAGES

English
German
Dutch



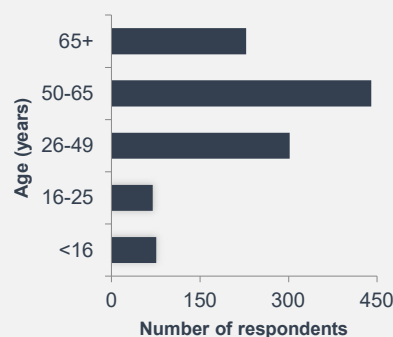
French
Italian
Turkish

GENDER PERCENTAGES FOR SURVEY 1



Similar percentages for survey 2

AGE DISTRIBUTION FOR SURVEY 1



AGE DISTRIBUTION FOR SURVEY 2

