

# Thank you for participating in the PROSPAX Natural History Study!

This study, funded by the European Joint Programme on Rare Diseases (EJP RD), aims to monitor people with genetically-confirmed ARSACS or SPG7 over 2 years, measuring the progression of their condition compared to healthy individuals.

### WHAT IS PROSPAX?

The PROSPAX (PROgression chart of SPAstic ataXias) project, which focuses on Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (ARSACS) and Spastic Paraplegia Type-7 (SPG7), is a collaborative effort between neurologists across several sites throughout Europe and Canada. The overall aim is to gain a better understanding of how spastic ataxias progress over time to prepare well-designed treatment trials for these conditions that will be applicable to many of the >100 other spastic ataxias. This is called 'trial-readiness'.

### WHICH DATA IS BEING COLLECTED FROM THE ASSESSMENTS?

#### **CLINICAL**

#### **DIGITAL**

#### SELF-REPORTED

#### **BIOMARKER**

- **Scale for the Assessment** and Rating of Ataxia (SARA) score at baseline, Y1 & Y2
- **Spastic Paraplegia Rating** Scale (SPRS) score at baseline, Y1 & Y2
- **ARSACS Disease Severity Index** at baseline, Y1 &Y2

SPG7

- **Assessment of** walking pattern and movement with body-worn sensors (APDM wearables).
- **Assessment of** upper limb movement and foot tapping with a force sensor (Q-motor)
- **Specific** aspects of physical, mental and social health monitored via questionnaires

at baseline, Y1

Healthy

controls

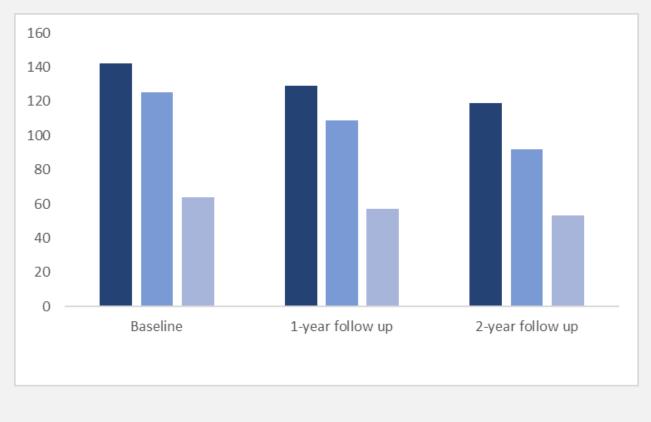
& Y2

**Optical Coherence Tomography (OCT)** to capture the thickness of the retina layer of the eye

**IMAGING** 

- MRI brain scans to map the structures underlying SPG7 and ARSACS to assess progression
- **Blood-based** biomarkers which can show signs of nerve damage

## NUMBER OF PARTICIPANTS RECRUITED



ARSACS

Cambridge, **England** 

Paris, France

Tübingen and Essen, Germany



Pisa, Italy

Nijmegen, **Netherlands**  Istanbul, **Turkey** 

Quebec, Montreal and Saguenay, Canada

PARTICIPANTS RECRUITED FROM 7 COUNTRIES

<sup>\*</sup>For some of the above categories of the study, only some subsets of participants are involved