



PROSPAX RESEARCH PROJECT

The **PRO**gression chart of **SP**astic **ataX**ias (PROSPAX) research project, launched in September 2020, is a novel collaborative effort between several neurologists across Canada and Europe, including the UK. The Ataxia Charlevoix-Saguenay Foundation is one of the 3 patient advocacy organisations participating in this 3 year project. This ambitious project aims to study the progression of spastic ataxias over time, in a rigorous and harmonised way – from the clinical to the molecular level, including brain imaging, identifying markers of progression and studying animal models. The following neurologists and their respective teams are participating in the project :

Dr. Matthis Synofzik, Neurodegenerative Diseases Hertie-Institute for Clinical Brain Research, Tübingen, Germany

Dr. Bernard Brais, Montreal Neurological Institute and Hospital, Montreal, Canada

Dr. Cynthia Gagnon, University of Sherbrooke, Sherbrooke, Canada

Dr. Bart Van de Warrenburg, Radboud University Medical Centre, Netherlands

Dr. Filippo M. Santorelli, IRCCSFondazione Stella Maria, Pisa, Italy

Dr. Marcus Krüger, Center Molecular Medicine, Cologne, Germany

Dr. Sophie Tezenas du Montcel, Pierre and Marie Curie University, Paris, France

Dr. Rita Horvath, University of Cambridge, Cambridge, UK

Dr. Nazli Basak, KOç University, Istanbul, Turkey

The German Hereditary Ataxia & Euro Ataxia (in Germany and in the UK) and the Euro-HSP organisations in France are the other 2 patient advocacy organisations participating in the research.

The PROSPAX project will focus on two conditions - ARSACS and SPG7. However, this survey is open to anyone with any type of ataxia or hereditary spastic paraplegia (HSP). This survey is your chance to have your voice heard by researchers, to make sure that the questions they are trying to answer are the ones that are important to you as a person living with the condition.

The researchers involved in the PROSPAX project are very keen to ensure that they focus their research on what the important challenges are for people living with spastic ataxia. In order to help them achieve this, we are gathering information directly from all people with ataxia or HSP about the symptoms and challenges of living with ataxia or HSP. They will use the information gathered by this survey to plan their research.

We would be grateful if you could spend a few minutes (approximately 5 minutes) completing the questionnaire **by January 15, 2021**. To participate, click on <https://www.surveymonkey.co.uk/r/7MJLRKR>

On behalf of the PROSPAX research team, the Ataxia Charlevoix-Saguenay thanks you in advance for participating in this survey and for your important contribution to this research project.