



FOR IMMEDIATE RELEASE

The National Ataxia Foundation and Ataxia Canada Announce New Natural History Study Site in Montreal for Spinocerebellar Ataxia Patients

Minneapolis, MN (August 15, 2022) – The National Ataxia Foundation today announced that the Centre hospitalier de l'Université de Montréal (CHUM) will be the first international clinical site to join the Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA).

The CRC-SCA is a group of clinical research sites across the United States actively enrolling patients into a natural history study of Spinocerebellar Ataxias. The addition of CHUM marks the 15th site to join the Consortium and the first site to join outside of the United States. Located in Montreal, Québec, the CHUM clinical site was selected through a collaboration with Ataxia Canada and will be led by experienced ataxiologist, Dr. Antoine Duquette.

The goal of the CRC-SCA is to understand how Ataxia progresses without intervention and identify factors that may alter disease progression in patients. “Natural history data, like that collected through the CRC-SCA, is critical for the design of future successful clinical trials in Ataxia. NAF is proud to partner with Ataxia Canada and CHUM to provide the Ataxia community a new clinical site that empowers individuals to participate in this important research,” said Andrew Rosen, Executive Director at the National Ataxia Foundation.

“We know that many Canadian patients want to be a part of the research initiatives and a natural history study can provide a big picture view of how a disease develops and improve understanding of that condition. These findings may be used to fuel drug development. These studies also help researchers design clinical trials well suited to the patient population and disease,” said François-Olivier Théberge, General Manager at Ataxia Canada.

CHUM will begin enrolling patients to the CRC-SCA's natural history study. Antoine Duquette, MD, MSc, FRCP(C) said, "We are extremely happy to join the Consortium and several patients have already expressed strong interest in the natural history study. For rare diseases, such coordinated efforts at national and international levels are essential to advance research. They also pave the way towards clinical trials, an essential step to find a cure for these devastating diseases. The National Ataxia Foundation and Ataxia Canada are powerful advocates for Ataxia patients and we expect this innovative partnership to have, down the road, a major impact on patient care."

To learn more, contact us or visit NAF's website at www.ataxia.org

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About NAF

Ataxia is a rare neurological disease affecting tens of thousands of people in the US and many thousands more around the world. It is progressive, affecting a person's ability to walk, talk, and use fine motor skills. Founded in 1957, NAF is a Minneapolis-based nonprofit organization established to help persons with Ataxia and their families. The Foundation's vision of a world without Ataxia will be accomplished through its primary programs of funding Ataxia research, providing vital programs and services for Ataxia families, and partnering with pharmaceutical companies in the search for treatments and a cure. NAF works closely with the world's leading Ataxia researchers, promoting exchanges of ideas and innovation in Ataxia discovery.

About Ataxia Canada

Ataxia Canada – Claude-St-Jean Foundation is first and foremost a community of women, men, adults, teenagers, and children suffering from many forms of ataxia, in all corners of the country. Ataxia Canada is 50 years of substantial progress and small resolute steps towards the implementation of programs to better the quality of life of ataxic patients. It is also 50 years of steady scientific advances towards a cure through research and clinical trials conducted by seasoned researchers of international renown from here and abroad.