Assessment based on input from patients with recessive ataxia

Ms. Marjolaine Tremblay’s project
Groupe de recherche interdisciplinaire sur les maladies neuromusculaires de Jonquière (Québec)

Ms. Marjolaine Tremblay, a social worker and doctoral student at the Groupe de recherche interdisciplinaire sur les maladies neuromusculaires (GRIMN) in Jonquière (Québec), is currently developing a questionnaire to assess the impacts of ARSACS (or any other type of recessive ataxia) based on the perception of the individuals living with ARSACS. This important project is under the supervision of Dre. Cynthia Gagnon and Dr. Bernard Brais.

When new treatments are tested, researchers need measurement tools to evaluate their effects. Among these tools, there are questionnaires that measure the impact of treatment according to the input of the people affected. The questionnaire under development could therefore be used in therapeutic trials for ARSACS and also for other purposes by health professionals.

Ms. Tremblay’s project is funded by the PREPARE initiative (of which the Charlevoix-Saguenay Ataxia Foundation is a financial partner), the Fonds de recherche du Québec en santé and the Corporation de recherche et d’action sur les maladies héréditaires.

To learn more about GRIMN projects, visit Facebook: https://bit.ly/2LaOnn4

January 26, 2019