Frequently Asked Questions: Canadian Proactive Cohort for People Living with Multiple Sclerosis (CanProCo)

November 2018

1. **What is the Canadian Proactive Cohort for People Living with Multiple Sclerosis(CanProCo)?**

The Canadian Proactive Cohort for People Living with Multiple Sclerosis (CanProCo) will allow researchers and clinicians to observe a large group of people living with MS from across Canada over a period of time and collect specific information from them that will identify characteristics of MS progression, specifically, why and how progression occurs. This knowledge aims to improve diagnosis, treatment, long-term monitoring and potential prevention of progression in MS. The CanProCo will also serve as a rich source of information and resource available to other experts in MS, as well as other neurological diseases for ongoing research.

2. **What information will be gathered from the cohort?**

Researchers will collect and analyze new information over time but will also look at existing health data. They will develop a set of research questions about progression pertaining to three main themes: *mechanisms of progression* (e.g. how does progression occur at the cellular level and what biological markers can be used to track progression?), *treatments/real-world evidence* (e.g. how do existing treatments for MS impact progression and what role does early diagnosis and self-management play?) and *impact* (what is the impact of progression on the health system, society, the economy, and the person's quality of life?). To answer these and other questions, the researchers will collect different types of information such as biological samples, imaging data, clinical data (i.e. symptoms and treatment responses), and information about lifestyle, disability, healthcare costs, aspects of daily living and quality of life. With this information, researchers will create a clearer picture of how progression affects an individual physically, emotionally, economically and socially.

3. **How will a study like this impact those living with MS?**

The results of this study have the potential to change the way we diagnose and treat MS, how people live with MS, and how we talk about MS progression altogether. This is a significant pursuit of knowledge, one that could dramatically change the landscape about what we know about MS and MS progression.

Participants of this study will have an opportunity to examine their own behaviours and make connections to others living with MS in hopes of finding common ground. MS affects each individual in unique and unpredictable ways making it crucial to study and understand each

person's own experience over time. This study will provide those living with MS new opportunities for treating progressive MS and other neurodegenerative diseases while addressing important public health matters such as access to treatment and impact of long-term disability on the health-care system.

4. Why a Canadian MS Cohort study?

Canada has one of the highest rates of MS in the world. There are currently no nationwide studies of this kind being done in Canada. Given the tight-knit community of MS clinical and research experts across the country, the funding partners recognized a valuable opportunity to bring these experts together to collect and analyze data from people living with MS to understand disease progression. A pioneering and innovative study, the CanProCo will provide a means to compare biological, clinical and quality of life data from across the country, while building an open, centralized Canadian resource that can be used for research purposes.

This study will also strengthen the relationships between industry, non-profit, academia, and government.

5. How much funding is required for this initiative and who is supporting it?

Up to $7.125 million has been secured to support this initiative, with potential for increased support from other partners as the project continues. The MS Society of Canada, Brain Canada, and Biogen are each contributing more than $2 million to the project. The MS Society is grateful to lead donors, Bennett Jones LLP and PCL Construction for their generous support of $1 million and $1.25 million, respectively, as well as several other significant contributors. Funding partner Brain Canada receives financial support from Health Canada through the Canada Brain Research Fund.

6. How long will the MS Progression Cohort be studied for?

The progression cohort is a five (5) year initiative, which will allow the research team to develop and study the cohort with the potential for ongoing research and data collection beyond the five-year funding term.

7. Are there other similar cohort studies taking place?

Although there are studies taking place in other countries that are similar to the CanProCo, this is the first study of its kind in Canada designed to answer fundamental questions related to progression in MS and serve as an invaluable tool available to the MS research community.

8. How was the research team selected?

The funding partners released a request for applications (RFA) that invited interested research teams to apply for funding to design and implement the cohort study. The RFA consisted of two

stages. First, $250,000 was awarded to a team to plan and design the cohort study. Second, the team submitted a more fulsome application that outlined in detail how they would identify and recruit participants, collect and analyze data, and ensure a coordinated research effort across the country. A rigorous independent review process was implemented to select the team that will be leading this large initiative and included a review panel of international research and clinical experts and a person affected by MS.

9. When will the CanProCo project begin?

Recruitment for the cohort is anticipated to begin in early 2019.

10. Who will be eligible to participate in the CanProCo?

The study will recruit 1,000 individuals, aged 18-60, with a diagnosis of either relapsing-remitting MS, primary-progressive MS or radiologically isolated syndrome (RIS). Interested participants must also have an EDSS score of 6.5 or lower and must be within 10 years of disease onset.

This is not the complete list of inclusion criteria. For more information please visit the research portal (to be updated once recruitment begins).

The study was designed to include targeted populations of patients that will scientifically allow the team to assess progression in the most efficient way possible. This is why it is not possible to include all people living with MS, but the team hopes that by studying targeted groups of patients they will be able to achieve the study goals.

11. What are the sites that will be recruiting participants?

The following five sites will be recruiting participants:

- University of Alberta MS Clinic
- University of British Columbia MS Clinic
- University of Calgary MS Clinic
- University of Toronto MS Clinic
- Centre Hospitalier de l'Université de Montréal MS Clinic

12. Can I participate in the cohort?

Once recruitment begins, information for interested participants will be available on the MS Society research portal website. Interested participants can also contact Melanie Guenette, lead research coordinator, at guenettem@smh.ca.

13. What will the researchers collect and how long do I have to participate in the cohort?

The researchers will perform magnetic resonance imaging (MRI), clinical assessments, collect blood and cerebral spinal fluid and other information. Not everyone will be required to participate

in all components of the study, however, participants will be required to visit the clinician on a yearly basis for at least five years.

For more information, please contact the MS Society of Canada at msresearchgrants@mssociety.ca.