

December 12, 2022

Re: Brief for SRSR Study on International Moonshot Programs

Dear Members of the Standing Committee on Science and Research:

Thank you for the time and effort you have put into your important role as a member of the SRSR Committee. We were very interested to learn about your study on International Moonshot Programs.

We would like to submit to the SRSR Committee that understanding the brain - in health, development, disease, and resilience – is an imperative moonshot that will be critical to Canada's well-being in the 21st century.

I am writing on behalf of Dystonia Medical Research Foundation (DMRF) Canada - the only organization in Canada that is dedicated to improving the lives of those living with dystonia - a neurological disorder that causes excessive, involuntary, painful muscle contractions. In addition to causing abnormal movements, depression and anxiety are common non-motor symptoms of dystonia. There is currently no cure for dystonia. DMRF Canada's mission is to advance research for more treatments and, ultimately, a cure; to promote awareness and education; and to support the needs and well-being of affected individuals and families.

We estimate that dystonia affects approximately 50,000 Canadians; however, because of insufficient research in Canada, this is an extrapolation based on US data. We do know that when we look at the dozens of diseases that can cause dystonia symptoms (such as Parkinson's, Huntington's, and Multiple Sclerosis), the instance of individuals living with dystonia could be in the millions.

Investment in research is needed to better understand dystonia - and other neurological conditions - in order to improve diagnosis and care. The most critical issues that our community faces are:

- Access to early diagnosis, comprehensive treatment, and care - In a 2019 survey, DMRF Canada found that it took patients more than one year to receive a proper dystonia diagnosis for 63% of those surveyed. For 45% of those individuals, it took more than 4 years, and for 16%, it took more than 10 years.
- Lack of effective treatments - In another survey, only 13% of individuals treated with neurotoxin injections (the most common treatment for dystonia) reported it helped keep their dystonia under control. (DMRF Canada, 2016)

These challenges could be significantly improved through an investment in research towards a better understanding of the conditions, better treatments, and ultimately a cure.

Currently, DMRF Canada partners with the DMRF USA to invest in research for dystonia, which is often outside of Canada, while also engaging with the Dystonia Coalition (funded by National Institutes of Health USA) - a collaboration of medical researchers and patient advocacy groups from across the globe.



As a member of the Neurological Health Charities Canada (NHCC), DMRF Canada also works with other organizations focused on neurological conditions to work towards our shared goals: enhanced research and support for those living with the conditions. We also collaborate with the Canadian Movement Disorders Society, an affiliate of the Canadian Neurological Sciences Federation (CNSF), and the Movement Disorder Society (MDS); a group of healthcare professionals and scientists whose mission is to foster collaboration, knowledge exchange, education, advocacy, and research and to collaborate with the international community of movement disorders science and clinical practice. These movement disorders include a range of neurological disorders.

Tackling the enormous societal challenge and urgent need to understand the human brain has united a broad, diverse coalition of Canada's current and future leaders in neuroscience and mental health research in alliance with Indigenous Knowledge Holders, patients, and families impacted by brain disease or injury, health charities, private and public science funders, and industry.

With the Canadian Brain Research Strategy, we have strong strategic coordination and collaboration between stakeholders across sectors to create a collective national research strategy for targeted brain and mental health investment. We have the network, partnerships, and vision in place. We need the funding to catalyze this coalition into concerted, bold, and concrete action.

The time to invest in a Brain Moonshot for Canada is now.

Sincerely,

Archana Castelino
National Director
Dystonia Medical Research Foundation Canada

References:

DMRF Canada. (2016). Real Patients, Real Results: The Dystonia Canada Survey Report. Retrieved from www.dystoniacanada.org: <https://dystoniacanada.org/survey>