

Final Call for Project Proposals – Funding Available

Newborn Screening for Spinal Muscular Atrophy in Canada

Wednesday September 15, 2021 – Muscular Dystrophy Canada (MDC) is calling for proposals for the funding of projects to implement newborn screening (NBS) for spinal muscular atrophy (SMA) across Canada. It is anticipated that these projects will be led by labs or clinicians (or both) and should either focus on setting the lab up for testing or ensuring efficient uptake of policy (i.e., addition of SMA to existing provincial newborn screening panel).

Background

In December 2020, MDC launched a multi-year, multi-phase endeavour in collaboration with Novartis Pharmaceuticals Canada Inc. The key priority for this collaborative project is to better understand and address barriers for the implementation of NBS for SMA across Canada and to positively influence policy change, such that SMA is prioritized for imminent inclusion on existing provincial NBS panels. To date, the initiative has included many stakeholders across Canada including patients and their families, medical and academic community members, like-minded patient organizations, governments and industry. In addition to Novartis Pharmaceuticals Canada Inc., individual donors and supporters have expressed interest and enabled MDC to undertake this initiative.

There are 5 phases in this collaborative initiative:

- ~~1. Completion of a needs and readiness assessment to better understand the state of readiness of provinces and territories as well as health institutions (laboratories, hospitals, clinics) for newborn screening for SMA.~~
- ~~2. Initial funding call for sites to offer newborn screening for SMA.~~
- 3. Secondary funding call for sites to offer newborn screening for SMA.**
4. Evaluation and knowledge transfer & exchange. Work with stakeholders to ensure policy adoption across all provinces and territories.
5. Present SMA as a case study for harmonized newborn screening in Canada.

To learn more: <https://muscle.ca/services-support/newborn-screening/>

Current Status

Ontario is the only province in Canada that currently provides NBS for SMA. A standardized diagnosis to treatment pathway was created that facilitates timely access to care for SMA patients, as well as optimizing motor function, and prolonged life expectancy.

To expand on the success of Ontario, in April 2020, ETIO Public Health Consultants Inc. was engaged to complete Phase 1 - an assessment for the viability of including SMA into existing newborn screening programs in addition to a potential future national screening program. This assessment was meant to elicit a clear understanding of the current barriers and facilitators in the current operational and policy landscape with respect to newborn screening. Clear findings from the multitude of subject-matter experts from across the country, review of existing literature and the promising data from Ontario, point to strong support and potential for SMA inclusion in NBS panels in other provinces and territories.

We are now calling upon teams of labs and clinicians within each province to submit a proposal for a project that will lead to the provincial implementation of NBS for SMA.

Who can apply?

MDC is seeking to support and leverage the work of laboratory and/or clinical stakeholders within each province, outside of Ontario, on development of projects. This funding call is open to all clinicians who provide care for those affected by SMA, clinicians involved in newborn screening and/or members of provincial laboratories conducting newborn screening. Projects should include engagement with a diverse range of parties who may have interests or expertise in the subject or the approaches proposed. MDC expects one project proposal for each province. However, for certain regions (e.g., Atlantic, territories), we expect a proposal from members of different provinces/territories.

Eligible activities

Eligible activities include projects that are intended to adequately prepare and promote inclusion of SMA into an existing NBS panel. For example, a project can be setting up the provincial laboratory to test for SMA samples, determining best practices/testing the process of NBS for SMA. The activities are not meant to be research-focused, but rather ones that actively lay the groundwork and ramp up the jurisdiction for long-term sustainability and policy uptake.

How funding will be allocated?

MDC, together with a committee composed of clinical and academic NBS experts from North America and Europe, will review the proposals and may ask potential recipients clarifying questions via email or to present their proposal via a virtual 40-minute presentation.

How to submit an expression of interest

Expressions of interest should be 2-pages long and include:

- Brief summary of current state of newborn screening in your province and indicate the primary barrier/gap;
- Provide a detailed overview of the project you propose will address this gap;
- Provide a rationale for the approach you are proposing; indicate the expected contribution of the project to the funding opportunity's stated objectives;
- What makes your province/team ready to address this gap?
- Indicate the project's proposed engagement with clinicians and labs;
- Indicate the potential influence and impact of your project in informing practice and policy uptake;
- How will your project lead to your province's implementation of NBS for SMA and when is the anticipated provincial uptake?

Budget and project timelines

- Please submit a detailed budget with timelines for key milestones alongside your application. A maximum budget has not been allocated per project.

Conflicts of Interest

- All applicants must identify funding received for NBS for SMA from other sources and all other disclosures.

The expression of interest, budget and anticipated timelines can be sent directly to homira.osman@muscle.ca in Microsoft Word or PDF format. For questions about the process, please contact Homira Osman.

Deadlines

Expressions of interest must be received by **October 15, 2021 11:59PM EDT**. Projects that are approved for funding would need to begin by December 2021.

Recipients and the amount of funding allocated will be made available at a later date.

About MDC | Since 1954, Muscular Dystrophy Canada has been the leading voice of the neuromuscular community in Canada. Thanks to our generous donors, we support individuals impacted by neuromuscular disorders, by investing in research, delivering critical programs and services, and challenging public policy. Funded by Canadians from coast to coast, our investment in the research community is advancing the development of important new treatments. Our programs and services play a critical role in informing and supporting members of the neuromuscular community by funding equipment to improve daily life; hosting family and caregiver retreats; providing emotional and educational support; and with providing access to vital resources and support systems. Our advocacy efforts focus on enhancing public policy at all levels of government to bring about positive change. We are currently working to bring new treatments and trials to Canada. Advances in medicine have resulted in individuals with neuromuscular disorders living longer but not necessarily living better. As their disorder progresses and changes, so do their needs and financial strains.

Our desire is to provide support through all stages of disease progression by providing the tools resources and support individuals need to live a full and rich life.