

30 January 2018

The Honourable Charles Sousa  
Minister of Finance  
c/o Budget Secretariat  
Frost Building North, 3rd floor  
95 Grosvenor Street  
Toronto ON M7A 1Z1

**Subject: Submission on 2018 Ontario Budget**

Dear Minister Sousa,

The Canadian Organization for Rare Disorders (CORD) is proud to have its national headquarters in the province of Ontario, nationally representing and serving 2.8 million Canadians directly affected by rare disorders and provincially nearly 1 million Ontarians. Indeed, with an estimated 7,000 rare disorders, there are more patients and families affected by rare disorders than with all cancers combined, with cardiovascular disease, or with diabetes.

Very importantly, CORD is very proud to have been a part of helping Ontario to become the first Canadian province to address the need for a government-led strategy for rare diseases.

In 2009, the European Union, in response to the underserved needs of those small patient populations affected by severe, debilitating and life-threatening conditions, called upon all 28 Member States to develop National Plans for Rare Diseases in collaboration with the patient community. In 2015, CORD led multi-stakeholder consultations to create Canada's Rare Diseases Strategy defining five core components: diagnosis, expert care, community support, access to therapies, and research.

In February 2016, Health Minister Hoskins set up a Working Group to develop Ontario's Rare Disease Strategy based on CORD's national model. Good to his word, following recommendations from the Working Group, this past October, Minister Hoskins put in place an Implementation Working Group with three Sub-groups directed to address these priorities: accelerate diagnosis (through genomic screening); propose a "hub-and-spoke" model to coordinate rare disease care; and establish a registry for rare disorders. We are especially pleased that CORD patient representatives are members of all three Sub-Groups and, as importantly, the Minister has set a deadline of June 2018 for an implementation plan.

Therefore, it is very timely for CORD to request that the Ontario government, in this coming 2018 budget, create a permanent funding programme that would allocate appropriate funds not only to implement the priorities and immediate recommendations as defined by the Implementation Working Group but also to assure that Ontario's Rare Disease Framework will be fully developed and sustainable. Only with dedicated and appropriate financial resources can Ontario plan to address the needs of patients and families today and to take advantage of the opportunities for prevention, treatment and care into the future.

As president & CEO of CORD and a member of the Implementation Working Group, I am personally very optimistic about the potential outcomes based on the expert leadership, dedicated staff, aggressive timeline and work thus far. Also, as current Chair of Rare Disease International, the global alliance of rare disease organizations representing more than 100 countries worldwide, I firmly believe Ontario is on the way to delivering a world-class Rare Disease Programme.

To achieve this vision, it will also be imperative that Ontario allocate appropriate budget designated for treatment, including genetic testing, specialist services, prescription medicines,

assistive medical devices, supportive care, and rapidly emerging next-generation gene and cellular therapies. These goods and services cannot be regarded as discretionary benefits but must be funded as essential components of an excellent Rare Disease Programme.

You may be assured that CORD and the entire rare disease community is committed to working with the government to assure the most effective and cost-effective use of our very precious resources.

Thank you for your leadership and support.

Sincerely,



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