

PROSPECTUS FOR SUPPORT - JAN 2021

CORD RARE DRUG STRATEGY



**THE NEED IS URGENT.
THE TIME IS SHORT.
THE OPPORTUNITY IS HUGE.**

Canada's rare disease community has the opportunity of a lifetime ... one that comes only once in a lifetime. After two decades of strident advocacy, CORD is stepping up its efforts to seize the opportunity to bring home Canada's first **Pan-Canadian Rare Drug Strategy**.

In February 2019, the Canadian government committed \$1 billion to a national *Rare Disease Drug Strategy* to be set up in 2022. In September 2020, in the Speech from the Throne, the government further committed to an overall Canadian *Rare Disease Strategy*, first presented by the Canadian Organization for Rare Disorders (CORD) to Parliament in 2015.

In October 2020, with a looming deadline and no action coming from the federal government, CORD launched an ambitious multi-stakeholder consultation program. We hosted a series of five (5) webinars and one national multi-stakeholder conference in December. Our plan was to continue web-based consultations in 2021 with an aspirational goal of delivering a consensus Rare Drug Plan by October 2021. Imagine our consternation to learn we must shift into “warp speed.” The federal government has indicated it will start consultations in January and wrap up by March. The good news is that the government has signaled it will coordinate its activities with CORD’s but that means we will have to accelerate our pace. With all signs pointing to a spring federal election, our revised goal is to complete an initial Rare Drug Program proposal by April 2021. This will be a platform for political engagement as well as public and stakeholder consultation to update and refine the proposal.

Between January and March 2021, CORD will host a series of Webinars and a national Rare Disease Day conference. While the exact schedule and topics will evolve as themes and issues emerge, our initial proposal includes the following.

1. Six Webinars using a similar format to the Fall 2020 Webinars
 - Case studies illustrating key challenges or best practices in rare drug access
 - Expert panelists representing various disciplines, expertise and perspectives
 - Interactive dialogue with participants
 - Recommendations and learnings

2. Topics to be addressed through the case studies
 - Comparative Canadian rare drug access: approvals and reimbursements
 - Pathways for access: Canadian and international examples
 - Innovative funding and financing for RD therapies
 - Managed access programs: what is needed to make these effective and cost-effective
 - Special access, early access, case-by-case access
 - Status and requirements for Canadian-based research and drug development
 - Diagnosis: newborn screening, next-generation sequencing, counselling, and follow-up referral
 - Creation of the network of rare disease expert centres

3. Rare Disease Day National Conference: A Consensus on Optimal Rare Drug Access

- What should be the role of a Pan-Canadian Rare Drug “entity”, a.k.a. program?
- Who needs to be included (governments, agencies with drug-related functions, private enterprises, healthcare providers, patient organizations, payers, academic researchers, others)?
- How should a Rare Drug pathway interface with existing agencies, authorities, and offices
- What elements must be (consistent) pan-Canadian? Which could or should be local, disease-specific, drug-specific, or not centrally defined?
- What is the ideal infrastructure and mode of coordination of activities along the access pathway?

4. Tentative Schedule

- Webinars 7, 8, & 9: January 29, February 12, February 26
- Rare Disease Day Conference: March 9 - 10
- Webinars 10 & 11: March 19, March 26
- Webinar 12: TBD

Our ASK: If you have ever believed in CORD and have supported us in the past, we ask you to step up with everything you can. Our commitment is to do everything we can. But we need your support to enable us lead the work: to commission the research, engage all stakeholders, and create a vision, and develop a program that will be endorsed by “just about” everyone.

CORD is proud of its partnerships with all stakeholders and is committed to transparency in recognizing contributions, including financial, in-kind donations, and volunteer support.



CHAMPION SPONSOR - \$20,000

- Registration for 4 representatives at the Rare Disease Day conference
- Prominent positioning of corporate logo on all conference materials
- Opportunity to provide corporate sponsored plenary speaker
- Participation in consultations and roundtables on Rare Drug Strategy
- Prominent recognition in final Rare Drug Strategy document
- Corporate recognition in Rare Drug Strategy (pre and post) reports

BENEFACTOR SPONSOR - \$15,000

- Registration for 3 representatives at the Rare Disease Day conference
- Prominent positioning of corporate logo on all conference materials
- Opportunity to provide corporate sponsored keynote speaker
- Participation in consultations and roundtables on Rare Drug Strategy
- Recognition in final Rare Drug Strategy document
- Corporate recognition in Rare Drug Strategy (pre and post) reports

LEAD SPONSOR - \$10,000

- Registration for 2 representatives at the Rare Disease Day conference
- Corporate logo on all conference materials
- Participation in consultations and roundtables on Rare Drug Strategy
- Recognition in final Rare Drug Strategy document
- Corporate recognition in Rare Drug Strategy (pre and post) reports

FRIEND SPONSOR - \$5,000

- Registration for 1 representative at the Rare Disease Day conference
- Corporate recognition on all conference materials
- Participation in consultations and roundtables on Rare Drug Strategy
- Recognition in final Rare Drug Strategy document



Canadian Organization
for Rare Disorders