Rare Disease Day 2017

March 30 - 31, 2017

Sheraton Vancouver Wall Centre
1088 Burrard Street, Vancouver, BC

Living Rare: With Research, Possibilities are Limitless

With Patients, Anything Imaginable is Achievable!

OBJECTIVES

- Share experiences of living … enhanced by a rare condition
- Connect with groups that improve rare living
- Create inspired and inspiring solutions within Canada's Rare Disease Strategy

BACKGROUND

- In 2007, CORD proposed an Orphan Drug Policy, which the federal government committed to and developed but is now entangled in Health Accord. Meanwhile enabling "orphan drug" guidances are being enacted but need much greater stakeholder awareness.
- In 2006, CORD led patient demonstrations advocating for a panCanadian Drugs for Rare Diseases access program; the governments created a Working Group that produced a proposal but then went dormant. A Working Group was resurrected in 2014, and despite little visible progress, access has improved although it is far from adequate.
- In 2015, CORD, following the lead of European countries and with multiple stakeholders, launched Canada's Rare Disease Strategy addressing five core areas: diagnosis, treatment and care, community support, access to drugs, and research. The Strategy was acknowledged by Parliament on Rare Disease Day 2016 and is the blueprint for Ontario's Rare Disease Strategy. An Ontario Working Group has been tasked to produce a report for February 2017.
- In 2005, Saskatchewan screened newborns for 29 genetic disorders but most other provinces screened for only 2 or 3 conditions. Patient advocates provoked the Ontario government to act and today it leads with 31 newborn tests. In 2016, all governments agreed to test for 22 core conditions, although most have yet to implement this consensus.

CORD Canadian Organization for Rare Disorders

Rare Disease Day 2017

March 30 - 31, 2017

Sheraton Vancouver Wall Centre
1088 Burrard Street, Vancouver, BC

FORMAT OF CONFERENCE

Through videos, testimonials, and facilitated discussions, we will provide an opportunity to get to know the people living with the rare conditions and their patient groups or organizations. Each of the four panels will be organized around one of the four core pillars of Canada's Rare Disease strategy: diagnosis, expert care, community support, and access to therapy. The fifth pillar, research, will be integral to addressing issues identified in each of the other areas.

The patients, family members, and care providers will bring to life shared and unique experiences of:

(1) seeking and making sense of a diagnosis as well as the challenges of living without a diagnosis;

(2) negotiating the uncharted route to the right specialists and navigating the care pathway, often without a GPS;

(3) finding (and sometimes starting) support network networks, both virtual and actual, and accessing community-based resources;

(4) knowing about and getting access to appropriate treatments, including experimental, approved, and off-label.

Following each patient session, a multi-stakeholder expert panel will reflect on the issues identified by the participants, the current status of each pillar in terms of service delivery, resources and capacity, gaps relative to needs, best practices elsewhere, and options for Canada.

All participants will engage in critique, reformulation, and recommendations for way forward.

Summaries of the sessions and overall recommendations will be prepared as the basis for the next steps in the planning for the implementation of Canada's Rare Disease Strategy.