Canadian Organization for Rare Disorders

Rare Disease Day 2018

Canada's Pathway to World Class Excellence in Rare Diseases

Pre-Conference Patients Day – March 20, 2018

Canadians' Access to Rare Disease Drugs: There shouldn't be winners and losers

Why: Canadian pathways for rare disease drugs give access to some patients but significant delay or deny access to many others. Those relying on public drug plans have much poorer access than those with private drug coverage.

What: A gathering of RD patients and families, some getting therapy, some still waiting, and some denied life-saving therapies, unite to make their stories known.

Where: Parliament Hill in Ottawa, prior to meetings with individual MPs

When: March 20, 2018

Rare Disease Day Conference – Day 1: March 21, 2018

Delta Ottawa City Centre, 101 Lyon Street, Ottawa, ON

Canada's Rare Disease Strategy: Building on Today's Capabilities to Create Tomorrow's Opportunities

1. How is Canada accelerating accurate diagnosis and referral?
2. What are we learning from current RD Centres of Expertise and what do we need to sustain and expand?
3. How are we planning to make next-generation gene and cell therapies available to Canadian patients?
4. What are opportunities for enhancing Canada's footprint in the development of therapies for rare diseases
    - Discovery, adaptation, and targeting drugs for rare conditions
    - Medical devices to improve capabilities and support quality of life
    - How can we create care communities that support and empower?

Awards Gala Dinner Celebration – March 21 – 6:00 pm

Delta Ottawa City Centre, 101 Lyon Street, Ottawa, ON

The evening of March 21st, CORD will host its annual Rare Disease Day Awards Gala. We will recognize those individuals and organizations that have made extraordinary contributions to the Canadian rare disease community over this past year.

Rare Disease Day Conference – Day 2: March 22, 2018

Canada's Pathway for Orphan Drug Approval: Dialogue with Health Canada

Day 2 (AM): Improving Access to Rare Disease Drugs in Canada

1. How can we assure Canadian regulations and guidelines provide a world-class pathway for clinical trials and approval of orphan and other specialty drugs?
2. How can Health Canada better engage with patients and advocates to meet needs of rare disease patients?
3. How can collaboration among all entities (Health Canada, PMPRB, CADTH/INESSS, pCPA, public and private drug plans, and industry) streamline the drug review process to expedite medicines to patients

Day 2 (PM): Applying "Systems Thinking" to Design "Managed Access" that Works

1. What have we learned from successful Canadian experiences with various forms of managed access to rare and specialty drugs?
2. What are best international examples of access to orphan drugs, including early and expedited access?
3. How can we better engage patients and caregivers to develop relevant outcome measures and to participate as partners in managed access?
4. What are system process requirements and contribution of all stakeholders to assure success of managed access to reduce risk and uncertainty while expediting access to patients with urgent and chronic needs?