



# CO-CREATING CANADIAN RARE FALL CONFERENCE 2025

NOVEMBER 25 - 26, 2025  
OTTAWA MARRIOTT HOTEL

This agenda outlines the full schedule of sessions, speakers, and activities planned for “Co-Creating Canadian Rare’ Fall Conference 2025, We look forward to a dynamic program focused on learning, networking & innovation.

## Day 1: Up Close and Personal with Rare

**Tuesday, November 25, 2025**

<b>7:00 AM - 9:00 AM</b>	<b>Rare Champions’ Breakfast: Parliamentarians, Patients, and Professionals</b> (by invitation only)
<b>9:30 AM - 10:30 AM</b>	<b>Rare Press Briefing</b> (by invitation only) <b>Speakers:</b> TBD
<b>11:00 AM - 12:00 PM</b> Victoria Ballroom	<b>Rare MultiVerse Canada 2025</b> Step into the World of Rare Innovation Welcome (CORD, Research Sponsors) Rare Portals (e.g. Diagnosis Dungeon, Genomics, Care Warriors)
<b>12:00 PM - 1:00 PM</b>	<b>Lunch</b>
<b>1:00 PM - 1:30 PM</b>	<b>Conference Opens</b> <b>Opening Plenary:</b> Canada Does Rare <b>Speakers:</b> Durhane Wong-Rieger, CORD; Jida El Hajjar, Loeys-Dietz Syndrome Foundation Canada; Federal Health Minister, Marjorie Michel (TBC); Vera Etches, CHEO

**1:30 PM - 2:00 PM**

**Optimizing Canada's Rare Disease Drug Strategy**

**Speakers:** Daniel McDonald, Health Canada; Mauro Chies, pCPA; Jida El Hajjar, CORD

**2:00 PM - 2:45 PM**

Workshop 1

**Expert Panel:** Living Rare in Canada: Diagnosis, Access, and Cost

- From Diagnosis to Treatment: FORGE to One for All-Kym Boycott, CHEO/Genome Canada
- Social and Economic Impacts of Living with Rare: Tania Stafinski, University of Alberta
- Living with Rare: Perspective of Caregiver and Physician: TBC

**2:45 PM - 3:00 PM**

**Break**

**3:00 PM - 4:30 PM**

Working Group 1  
(Parallel, Rotate)

**Working Groups:** Improving Rare Lives

- Ending the Diagnostic Odyssey and Beginning the Care Journey
- Hiding in Plain Sight: Finding Undiagnosed Patients with Funded Treatments
- Fit-for-Rare Alternative Pathways
- Public or Private Drug Plan? Rare Patients Still Left Out!
- Real Lives, Real Data, Real Impact: RWE that Matters to Payers, Policymakers, and Patients

**4:30 PM - 5:00 PM**

**Workshop Feedback**

**5:30 PM - 8:00 PM**

Summit (29<sup>th</sup> floor)

**Networking Reception\***

\*All conference participants are invited to attend.

**Day 2: From Ideas to Action**

## **Wednesday, November 26, 2025**

**9:00 AM - 9:05 AM**

**Welcome and Day 1 Recap**

Victoria Ballroom

**9:05 AM - 9:45 AM**

**Expert Panel:** Canadian Solutions Improving Rare Lives

- For the Cost of One Drug Vial – Case for SMA Multidisciplinary Clinic: Aaron Izenberg, Sunnybrook HSC
- RD Incubators in Canada: Daniel Gaudet, Ecogene-21
- ZebraCARE: When and Where Needed: Katrina Fontaine

**9:45 AM - 11:15 AM**

**Working Groups:** Improving Rare Ecosystem

Working Group 2

- RD Drug Strategy: Have We Accelerated Clinical Trials and Drug Launches?
- Drugs Need Support to Create Value for Patients and System
- Effective Transitions: Kids to Adults Living Well with Rare Disease
- Socioeconomic Impacts of LWRD and What We Must Do to Improve
- Integrating Rare Care: Horizontal, Vertical, Radial
- Neurological Breakthroughs – Is Canada Ready?

**11:15 AM - 11:30 AM**

**Break**

**11:30 AM - 12:00 PM**

**Workshop Feedback**

**12:00 PM - 1:00 PM**

**Lunch**

**1:00 PM - 1:30 PM**

**Solution Panel 1:** From Bench to Bedside to Global Population

**Panelists:** Celia Lourenco, DG BGTD; Risini Weeratna, National Research Council; Daniel Gaudet; Ecogene 21, Patient, Industry (TBC)

**1:30 PM – 2:00 PM**

**Solution Panel 2:** Canadian Network of Rare Disease Reference Centres

**Panelists:** Alexandra Cambier, CHU Sainte-Justine; François Bernier, CRDN; Leanne Ward, CHEO, Patient, Industry (TBC)

**2:00 PM – 2:30 PM**

**Solution Panel 3:** Canadian Rare Disease Ecosystem for Better Access to Clinical Trials and Innovative Therapies

**Panelists:** Thierry Lacaze, RareKids-CAN; INESS, CDA, Mina Rajan, ATTP; Industry (TBC)

**2:30 PM - 3:00 PM**

**Next Steps:** Recommendations for Canada's Rare Disease (Drug) Strategy, Phase 2

**All**