



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

7:00 AM - 9:00 AM **Rare Champions’ Breakfast: Parliamentarians, Patients, and Professionals** (by invitation only)

9:30 AM - 10:30 AM **Rare Press Briefing** (by invitation only)
Speakers: TBD

11:00 AM - 12:00 PM **Rare MultiVerse Canada 2025**
Victoria Ballroom Step into the World of Rare Innovation
Welcome (CORD, Research Sponsors)
Rare Portals (e.g. Diagnosis Dungeon, Genomics, Care Warriors)

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

1:00 PM - 1:30 PM **Conference Opens**
Opening Plenary: Canada Does Rare
Speakers: Durhane Wong-Rieger, CORD; Jida El Hajjar, Loeys-Dietz Syndrome Foundation Canada; Federal Health Minister, Marjorie Michel (TBC)

1:30 PM - 2:45 PM

**How Canada's Rare Disease Drug Strategy
Impacts Access**

**RDDS: Evaluation Framework Indicators of
Impact** Daniel McDonald, Health Canada

RDDS: Impact on Patient Access Sang Mi Lee,
Morse Consulting

RDDS: Demonstrating Patient Impact Maryam
Soleimani, BC Cancer (virtual)

2:45 PM - 3:00 PM

Break

3:00 PM - 3:30 PM

Panel: Right Pricing Rare Drugs for Timely,
Affordable and Sustainable Access

- PMPRB Guidelines Update: Guillaume Couillard (TBD)
- pCPA Update: Mauro Chiesi, pCPA

3:30 PM - 4:30 PM

Working Group 1

Working Groups: Improving Access and
Demonstrating Impact

- Hiding in Plain Sight: Undiagnosed Patients with Treatments
- Falling through Gaps in Public and/or Private Drug Plans
- Beyond Registries: Generating RWE that Matters to Payers, Policymakers, and Patients

4:30 PM - 5:00 PM

**Workshop Group Feedback
Day 1 Summary**

5:30 PM - 8:00 PM

Summit (29th floor)

Networking Reception*

*All conference participants are invited to attend.

Day 2: From Ideas to Action

Wednesday, November 26, 2025

9:00 AM - 9:15 AM

Welcome and Day 1 Recap Durhane Wong-Rieger

Victoria Ballroom

9:15 AM - 10:15 AM

Expert Panel: Canadian Solutions Improving Patient Journey

- Think Rare: From Undiagnosed to Clinical Care: Kym Boycott, Children's Hospital of Eastern Ontario
- For the Cost of One Drug Vial – Case for SMA Multidisciplinary Clinic: Aaron Izenberg, Sunnybrook HSC
- Ste Justine Centre of Expertise for Complement-Mediated Rare Diseases: Alexandra Cambier and Anne-Laure Lapeyraque, CHU Ste Justine
- ZebraCARE: When and Where Needed: Katrina Fontaine

10:15 AM - 10:45 AM

Panel: Social and Economic Impacts of Living with Rare Condition

- 2025 Canadian Survey of Patients and Families
- Impacts of Delayed Diagnosis and Treatment: Gina Cioffi, Chiesi USA

10:45 AM - 11:00 AM

Break

11:00 AM - 11:30 PM

Panel: Leveraging Evidence for Old and New Rare Drugs

- aTTP: New Evidence, New Hope: Mina Raja

- Fredreich's Ataxia: When Assessors Disagree: (TBC)
- FCS: 3rd Time Hits the Mark: Fiza Javed
- Rett Syndrome: Standardizing Heterogeneity: Sabrina Millson

11:30 AM - 12:30 PM

Working Group 2

Working Groups: Optimizing Patient Journey

- Transitioning Kids to Adults and Beyond
- Reducing Costs and Improving Quality of Life
- Bringing Care Close to Home When Patients are Not Close to Care
- Ultra-Rare Unique Challenges and Opportunities

12:30 PM - 1:30 PM

Lunch

1:30 PM - 2:00 PM

Working Group Feedback

2:00 PM - 2:45 PM

Reflections Panel:

Panelists: Risini Weeratna, National Research Council; François Bernier, CRDN; Leanne Ward, CHEO; Celia Lourenco, DG BGTD; Thierry Lacaze, RareKids-CAN; Sara Ethier, CORD; Alice Williams, CORD; INESSS, Industry,

2:45 PM - 3:00 PM

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

All