



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)

10:30 AM - 11:00 AM **Conference Registration** (Victoria Ballroom)

11:00 AM - 12:00 PM **Rare Experiences Canada 2025** (Balcony, Victoria Ballroom)

12:00 fghjkl **Lunch**

ccxcPM - 1:00 PM

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Conference Opens

Opening Plenary: Canada Does Rare

Durhane Wong-Rieger, CORD; Jida El Hajjar, Loeys-Dietz Syndrome Foundation Canada

1:30 PM – 3:00 PM **How Canada’s Rare Disease Drug Strategy Impacts Access**

RDDS: Evaluation Framework Indicators of

Impact Daniel McDonald, Health Canada; Sophie Sommerer, Biologics & Gene Therapies Directorate, François Bernier, Canadian Rare Disease Network, Thierry Lacaze, RareKids Can

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

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

RDDS: Leveraging Outcomes-Based Agreements Rebeccah Marsh, IHE

3:00 PM - 3:15 PM

Break

3:15 PM - 3:45 PM

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

- **PMPRB Guidelines Update:** Guillaume Couillard
- **pCPA Update:** Mauro Chies, pCPA

3:45 PM - 4:30 PM

Working Group 1

Working Groups: Improving Access and Demonstrating Impact

- **Using OBA Playbook to Improve Access**
Leads: Rebeccah Marsh & Sara Ethier
- **Assessing Impact of RD Drug Strategy Common List**
Leads: Alison Oliver & Krysta Davies Foss
- **Learnings from Rare Disease Drug Strategy 1.0 and Aspirations for RDDS 2.0**
Leads: Graham Statt & Wayne Critchley
- **Mind the Gaps from Regulator to Payer**
Leads: Sylvie Bouchard & Jida El Hajjar

4:30 PM - 5:00 PM

Workshop Feedback and Reflections Panel:

Graham Statt, Sang Mi Lee, Rebecca Marsh, Sylvie Bouchard, J & J (TBD); Roche (TBD); Sara Ethier, CORD; Lisa McCoy, CORD; Alison Oliver, Innomar Strategies

5:30 PM - 8:00 PM

Networking Reception*

Summit (29th floor)

*All conference participants are invited to attend.

Day 2: From Ideas to Action

Wednesday, November 26, 2025

8:30 AM - 9:00 AM

Breakfast (Victoria Ballroom)

9:00 AM - 9:05 AM

Day 1 Recap Durhane Wong-Rieger

9:05 AM - 9:15 AM

Investing in Canada's Rare Future Karen Helm, Alexion

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: Deborah Marshall, University of Calgary
- Impacts of Delayed Diagnosis and Treatment: Gina Cioffi, Chiesi USA

10:45 AM - 11:00 AM

Break

11:00 AM - 11:30 PM

Panel:

- aTTP: New Evidence, New Hope: Mina Raja
- Fredreich's Ataxia: When Assessors Disagree: François Theberge
- Rett Syndrome: Standardizing Heterogeneity: Sabrina Millson
- C3G: Targeting Rare Kidney Conditions, Aaren Jauhal, UHN

11:30 AM - 12:30 PM

Working Group 2

Working Groups: Optimizing Patient Journey

- **Transitioning Kids to Adults and Beyond:**
Leads: Aaron Izenberg & Susi Vander Wyk
- **Value of Preventing Crises: FOP and FCS**
Leads: Jida El Hajjar & François Theberge
- **Hiding in Plain Sight: Strategies for Finding, Diagnosis, and Treating**
Leads: Kym Boycott & Lindsay Williamson
- **Making the Case for Care** Leads: Karen Kelm & Katrina Fontaine

12:30 PM - 1:30 PM

Lunch

1:30 PM - 2:00 PM

Working Group Feedback

2:00 PM - 2:45 PM

Feedback and Reflections Panel:

Panelists: Risini Weeratna, National Research Council; François Bernier, CRDN; Sophie Sommerer, DG BGTD; Thierry Lacaze, RareKids-CAN; John Snowden, Amgen; Pfizer (TBD); Alice Williams, CORD

2:45 PM - 3:00 PM

Next Steps: Recommendations for Canada's Rare Disease (Drug) Strategy 2.0

All