



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 MultiVerse Canada (Victoria Gallery, 3 rd floor) Join us for a showcase of innovations, support systems, and partnerships—each offering a unique experience that brings together science, care, community, and empowerment.
12:00 PM - 1:00 PM	Lunch
1:00 PM - 1:30 PM	Welcome Address Maggie Chi, Parliamentary Secretary to the Minister of Health
	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 (90 min)**

Moderators: Bill Dempster & Durhane Wong-Rieger

**RDDS: Evaluation Framework Indicators of
Impact** Daniel McDonald, Health Canada; Sophie
Sommerer, Biologics & Gene Therapies Directorate;
Sapna Mahajan, Genome Canada; François Bernier,
Canadian Rare Disease Network, Thierry Lacaze,
RareKids-CAN (45 min)

RDDS: Impact on Patient Access Sang Mi Lee,
Morse Consulting (15 min)

RDDS: Demonstrating Patient Impact Maryam
Soleimani, BC Cancer (virtual) (15 min)

RDDS: Leveraging Outcomes-Based Agreements
Rebeccah Marsh, IHE (15 min)

3:00 PM - 3:15 PM

Break

3:15 PM - 3:45 PM

Panel: Right Pricing Rare Drugs for Timely,
Affordable and Sustainable Access
Moderator: Bill Dempster (30 min)

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

3:45 PM - 4:30 PM

Working Group 1

Working Groups: Improving Access and
Demonstrating Impact (45 min)

- **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:

Moderator: Bill Dempster (30 min)

Graham Statt, Sylvie Bouchard; Liam O'Fee, Roche; Sara Ethier, CORD; Alison Oliver, Innomar Strategies; Lisa Arbuckle, UCB Canada; Darren Partridge, Janssen

5:30 PM - 8:00 PM

Networking Reception* (Victoria Gallery, 3rd 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 Heim, Alexion (15 min)

9:15 AM - 10:15 AM

Expert Panel: Canadian Solutions Improving Patient Journey (60 min)

Moderator: Jida El Hajjar

- **Think Rare: From Undiagnosed to Clinical Care** Kym Boycott, Children's Hospital of Eastern Ontario (15 min)
- **For the Cost of One Drug Vial – Case for SMA Multidisciplinary Clinic** Aaron Izenberg, Sunnybrook HSC (15 min) (pre-recorded)
- **Ste Justine Centre of Expertise for Complement-Mediated Rare Diseases** Alexandra Cambier and Anne-Laure Lapeyraque, CHU Ste Justine (15 min)
- **ZebraCARE: When and Where Needed** Katrina Fontaine (15 min)

10:15 AM - 10:45 AM

Panel: Social and Economic Impacts of Living with Rare Condition (30 min)

Moderator: Durhane Wong-Rieger

- 2025 Canadian Survey of Patients and Families: Rebecca Marsh & Lesley Soril, IHE (15 min)
- Impacts of Delayed Diagnosis and Treatment: Gina Cioffi, Chiesi USA (15 min)

10:45 AM - 11:00 AM

Break

11:00 AM - 11:30 PM

Panel: (30 min)

- C3G: Targeting Rare Kidney Conditions: Arenn Jauhal, UHN
- Fredreich's Ataxia: When Assessors Disagree: François Theberge
- 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:**

Leads: Alice Williams & Cathy Evanochko

- **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: (45 min)

Moderator: Bill Dempster

Panelists: Risini Weeratna, National Research Council; François Bernier, CRDN; Sophie Sommerer, DG BGTD; Thierry Lacaze, RareKids-CAN; Alice Williams, CORD; Cathy Evanochko, TSC Canada

2:45 PM - 3:00 PM

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

All

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