

# Rare Disease Day 2026 Conference



From Foundations to Impact:  
Sustaining Momentum in  
Canada's Rare Disease Strategy

April 29–30, 2026  
Hyatt Regency Toronto

Access. Evidence. Readiness. Alignment.



Canadian Organization  
for Rare Disorders

Join leaders, advocates, researchers, healthcare professionals, and the rare disease community for two days of collaboration, innovation, and meaningful discussions.

Day 1: Theme: Measuring Progress — Sustaining Gains in Access

## Wednesday, April 29, 2026

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| 8:00 am – 9:00 am  | Registration & Breakfast ( <b>King Ballroom</b> )                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 9:00 am – 9:15 am  | <b>Welcome Address</b><br>Durhane Wong-Rieger, CORD                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 9:15 am – 9:45 am  | <b>Opening Plenary: Federal Evaluation: What Has Improved in Timely and Equitable Access?</b><br><b>Presenter:</b> Health Canada Rare Disease Director<br><b>Focus of Presentation:</b> <ul style="list-style-type: none"><li>• 12–18-month evaluation of provincial performance under the RD Drug Strategy</li><li>• Improved Timelines for listing drugs on the common drug list</li><li>• Variability reduction across provinces</li><li>• Evidence of improved access equity</li><li>• Areas where progress remains uneven</li></ul> <b>Takeaway:</b><br>The Strategy has produced measurable improvements. The question now is how to sustain and extend them. |
| 9:45 am – 10:15 am | <b>Respondent Panel</b><br><b>What the Data Tell Us — and What They Don't</b><br>Short responses from: <ul style="list-style-type: none"><li>• Provincial perspective</li><li>• Patient perspective</li><li>• Clinician perspective</li></ul>                                                                                                                                                                                                                                                                                                                                                                                                                       |

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|                     | <ul style="list-style-type: none"> <li>• Industry perspective</li> </ul> <p><b>Purpose:</b></p> <ul style="list-style-type: none"> <li>• Validate progress</li> <li>• Surface remaining friction</li> <li>• Identify blind spots (e.g., drugs outside the common list)</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 10:15 am – 10:30 am | <b>Break</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 10:30 am – 12:00 pm | <p><b>Session 1: Beyond the First List - Sustaining Momentum for New and Emerging Therapies</b></p> <p><b>Moderator:</b> TBD</p> <p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Drugs not on the initial common list</li> <li>• Therapies entering since Strategy implementation</li> <li>• Therapies without designated federal funding</li> <li>• Pipeline therapies expected in next 2–5 years</li> </ul> <p><b>Guiding Questions:</b></p> <ul style="list-style-type: none"> <li>• Will the gains seen in the first 12–18 months hold without targeted funding?</li> <li>• What mechanisms can extend accelerated listing beyond the initial list?</li> <li>• How do we prevent a two-tier system (funded list vs. non-listed therapies)?</li> </ul> <p><b>Output: Identify:</b></p> <ul style="list-style-type: none"> <li>• Structural risks to sustaining timely access</li> <li>• 2–3 mechanism options for maintaining momentum</li> </ul> |
| 12:00 pm – 1:00 pm  | <b>Lunch</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 1:00 pm – 2:15 pm   | <p><b>Session 2: Making Uncertainty Usable — Extending the Model to Future Therapies</b></p> <p><b>Moderator:</b> TBD</p> <p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Access with Evidence Development for non-listed drugs</li> <li>• Risk-sharing models for future pipeline</li> <li>• Alignment between regulatory approval and payer readiness</li> <li>• Data preparedness before submission</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |

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|                   | <p><b>Working Component:</b><br/>Define what would allow future drugs to benefit from similar acceleration — even without earmarked federal funding.</p> <p><b>Output:</b><br/>Concept outline for a scalable “future therapies pathway.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| 2:15 pm – 2:30 pm | <b>Break</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 2:30 pm – 3:45 pm | <p><b>Session 3: Provincial Readiness: Can the System Sustain Performance?</b></p> <p><b>Moderator:</b> TBD</p> <p><b>Reframe from:</b><br/>“Can the system absorb innovation?”</p> <p><b>Shift to:</b><br/>“Can the system sustain improved access as volume grows?”</p> <p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Capacity strains as more innovative therapies arrive</li> <li>• Genomic and diagnostic readiness</li> <li>• Rare disease centres, adequate resources, reach beyond geographic footprint</li> <li>• Data interoperability (across sources and sites)</li> </ul> <p><b>Output:</b><br/>Identification of system stress points that must be addressed to maintain equitable access.</p> |
| 3:45 pm – 4:30 pm | <p><b>Day 1 Closing Dialogue</b></p> <p><b>What Must Continue — and What Must Evolve?</b></p> <p>Structured around three categories:</p> <ol style="list-style-type: none"> <li>1. What must be maintained from the current Strategy?</li> <li>2. What must be adapted for new therapies?</li> <li>3. What must be built to prevent regression?</li> </ol>                                                                                                                                                                                                                                                                                                                                                                   |
| 5:00 pm – 8:00 pm | <p><b>Networking Reception</b> (Regency Ballroom)</p> <p>All conference participants are invited to attend.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

Thursday, April 30, 2026

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| 8:30 am – 9:00 am   | <b>Breakfast</b> (King Ballroom)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 9:00 am – 9:15 am   | <b>Day 1 Recap</b><br>Durhane Wong-Rieger, CORD                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| 9:15 am – 10:45 am  | <p><b>Session 4: From Research to Access - Preparing the Next Wave of Therapies</b></p> <p><b>Moderator:</b> TBD</p> <p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• From bench to pipeline readiness and contribution to care</li> <li>• Embedding regulator and HTA-relevant endpoints in development and trials</li> <li>• Engaging with patients from development toward therapeutic launch</li> <li>• Reducing red tape throughout development pathway from regulator to payer</li> </ul> <p><b>Output:</b><br/>Priorities for “Access-Ready Innovation.”</p> |
| 10:45 am – 11:00 am | <b>Break</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| 11:00 am – 12:00 pm | <p><b>Session 5: Integrated Care as Sustainability Infrastructure</b></p> <p><b>Moderator:</b> TBD</p> <p><b>Core message:</b><br/>Access acceleration is not durable without comprehensive care coordination.</p> <p><b>Focus:</b></p> <ul style="list-style-type: none"> <li>• Transitional care from screening to diagnosis to specialist</li> <li>• Virtual models for inclusive patient-centred care</li> <li>• Psychosocial, economic, education, occupation supports</li> <li>• Data interoperability (across sources and jurisdictions)</li> </ul>                       |

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|                           | <p><b>Output:</b><br/>Outline of scalable integrated care supports needed to sustain access gains.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>12:00 pm – 1:00 pm</b> | <b>Lunch</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>1:00 pm – 2:30 pm</b>  | <p><b>Session 6: Measuring What Sustained Momentum Looks Like</b><br/> <b>Moderator:</b> TBD<br/> <b>Working groups define:</b><br/> <b>Core indicators to track:</b></p> <ul style="list-style-type: none"> <li>• Time from approval to listing (beyond common list)</li> <li>• Variability across provinces</li> <li>• Access durability over time</li> <li>• Patient outcome impact</li> </ul> <p><b>Output:</b><br/>“Minimum Sustainable Access Indicator Set.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>2:30 pm – 3:00 pm</b>  | <p><b>Closing Plenary: Sustaining Momentum - A Credible Path Forward</b><br/> <b>Moderator:</b> TBD<br/> <b>Final framing:</b><br/> The Strategy has demonstrated measurable gains in access for designated therapies.<br/> The next challenge is structural:<br/> <b>How do we ensure that:</b></p> <ul style="list-style-type: none"> <li>• Newly arriving drugs</li> <li>• Non-listed therapies</li> <li>• Future pipeline innovations</li> </ul> <p>benefit from similar timeliness and equity?<br/> <b>Sustained momentum requires:</b></p> <ul style="list-style-type: none"> <li>• Scalable mechanisms</li> <li>• Shared risk tools</li> <li>• Data infrastructure</li> <li>• Provincial capacity readiness from screening/diagnosis to patient monitoring/management from local to remote</li> </ul> <p>Not a restart — but durable drug access integrated in comprehensive system</p> |
| <b>3:00 pm – 3:30 pm</b>  | <b>Wrap-up and Next Steps</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |