Canadian Organization for Rare Disorders

RARE CANADA

Building the Next Phase of Diagnosis, Treatment, Care and Community Support for People with Rare Diseases

FALL 2026 RARE DISEASE CONFERENCE

November 12-13, 2026

Delta Halifax Downtown
1990 Barrington St, Halifax, B3J 1P2

A two-day gathering of patients, caregivers, patient organizations, health professionals, researchers, policymakers, health-system leaders, technology and data experts, value assessors, industry and Canadian and international rare disease leaders.

RARE DISEASE FIRST.

Innovation that reaches further.

A defining moment for rare disease in Canada

Canada's Rare Disease Drug Strategy began with an essential commitment: improving access to therapies for people living with rare diseases and reducing the inequities created by geography, diagnosis and treatment availability.

Phase 1 has created important momentum through dedicated federal investment, new provincial and territorial agreements, greater attention to rare disease medicines, and emerging commitments to diagnosis, evidence generation and system infrastructure.

Phase 2 is the opportunity to protect and strengthen access to therapies while building the pathways that determine whether people are recognized early, diagnosed accurately, connected to expertise, matched to appropriate treatment and supported throughout their lives.

READINESS	EVIDENCE	TIMING
CORD's Rare Disease Readiness Assessment identifies system gaps, provincial variation and areas of emerging strength.	Lessons from Phase 1 implementation and evaluation provide a foundation for a more focused, accountable next phase.	The November conference is timed to inform fall 2026 budget development and continuity beyond March 31, 2027.

Conference purpose

Next Generation Rare Canada will convert evidence, lived experience and innovation into a focused national action portfolio for RDDS Phase 2.

- Protect and strengthen equitable and timely access to rare disease therapies.
- Advance earlier diagnosis, individualized treatment and integrated lifelong care.
- Connect specialist networks, local services and properly enabled rare disease communities.
- Build patient-accessible data and evidence systems that improve care and support accountability.
- Select realizable initiatives with visible results within the Phase 2 period.

The program draws on Canadian advances in genomics, AI-assisted identification, precision therapies, patient-centred data and community care; the UK Rare Diseases Framework and Action Plans; Canada–US collaboration; and the emerging WHO global agenda.

Committing to Rare—and building a future for all

to rare disease medicines while investing in the diagnostic, clinical, community and data capabilities required to deliver meaningful outcomes.

The ambition is practical and measurable: a concentrated set of changes that Canada can implement, demonstrate and scale during the Phase 2 period.

01

Find Rare Earlier

Identify people earlier and more accurately through recognition, newborn and population screening, genomic and other advanced diagnostics, family-based identification and responsible AI-assisted case finding.

02

Match Treatment and Care to the Person

Create individualized therapeutic and care pathways informed by the condition, molecular mechanism, clinical characteristics, personal goals, family context and life circumstances.

03

Bring Rare Expertise and Support Closer to Home

Connect national and provincial specialist expertise with local professionals, communities and patient organizations while maintaining health-system accountability for care.

04

Learn with and from Every Rare Disease Patient

Develop patient-accessible, patient-informed data systems that support care, treatment decisions, evidence generation, system improvement and research.

Rare diseases remain the first priority, the principal partnership and the central measure of success.

> **“Build it first and well for rare disease.**
>
> **Then use what rare disease teaches us to improve care more broadly.”**

Capabilities developed for rare disease will also inform care for rare genetic and molecular forms of more common conditions, small treatment-responsive subgroups and emerging precision approaches. This wider benefit remains secondary to the direct commitment to people with rare diseases.

TWO DAYS OF INSPIRATION, DESIGN AND COMMITMENT

A conference to enable action

The conference combines lived experience, international learning, Canadian innovation and structured creative engagement. Participants will build, test and prioritize a realizable Phase 2 portfolio rather than review a pre-set plan.

MOMENTS THAT MATTER

Patient and caregiver experiences frame the challenge, test proposed solutions and define the outcomes that matter.

FUTURE IN PRACTICE

Short demonstrations bring genomics, AI, individualized therapy, patient-driven data and community care to life.

DESIGN STUDIOS

Mixed stakeholder groups work from future patient experiences back to first-year actions and three-year results.

BOUNDARY CASES

New cases span ultra-rare disease, hidden rare within common diagnoses, molecularly defined conditions and care without a disease-modifying therapy.

PRIORITY CHOICES

Participants assess transformative value, realizability, equity, readiness and investment requirements.

PARTNERSHIP COMMITMENTS

Organizations identify assets, implementation sites, collaborators and actions required from government.

Who will participate

Patients and caregivers • patient organizations • clinicians and other health professionals • researchers • health technology and data experts • HTA and value assessment leaders • policymakers • health-system decision-makers • industry • Canadian and international rare disease experts

Realizable conference outputs

1. **Next Generation Rare Canada Action Portfolio**
   A focused group of Phase 2 demonstrators across diagnosis, treatment, care, data and community support.
2. **Phase 2 Investment Proposition**
   A clear case for continued drug funding and the enabling capabilities required to deliver meaningful outcomes.
3. **Readiness-to-Innovation and Three-Year Milestone Map**
   Priority gaps linked to Canadian assets, first-year actions, measurable results and pathways for scale.
4. **Partnership Compact and First 100-Day Agenda**
   Named contributors, initial conveners and immediate actions following the conference.