

VIA EMAIL

October 13, 2026

Federal, Provincial and Territorial Ministers of Health

Hon. Marjorie Michel, Minister of Health, Canada
Hon. Ravi Kahlon, Minister of Health, British Columbia
Hon. Adriana LaGrange, Minister of Hospital and Surgical Health Services, Alberta
Hon. Jeremy Cockrill, Minister of Health, Saskatchewan
Hon. Uzoma Asagwara, Minister of Health, Seniors and Long-Term Care, Manitoba
Hon. Sylvia Jones, Deputy Premier and Minister of Health, Ontario
Hon. Sonia Bélanger, Minister of Health, Quebec
Hon. John Dornan, Minister of Health, New Brunswick
Hon. Michelle Thompson, Minister of Health and Wellness, Nova Scotia
Hon. Cory Deagle, Minister of Health and Wellness, Prince Edward Island
Hon. Joedy Wall, Minister of Health and Community Services, Newfoundland and Labrador
Hon. Brad Cathers, Minister of Health and Social Services, Yukon
Hon. Lucy Kuptana, Minister of Health and Social Services, Northwest Territories
Hon. Janet Pitsiulaaq Brewster, Minister of Health, Nunavut

Subject: Open letter: Building Phase 2 of Canada's rare disease strategy

Dear Ministers,

Canada has made important progress for people living with rare diseases. Now is the time to build on it.

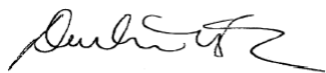
On behalf of the Canadian Organization for Rare Disorders (CORD), I am sharing our open letter calling on Canada's health ministers to work together to secure a strong and sustainable Phase 2 of the National Strategy for Drugs for Rare Diseases, starting this week at the Health Ministers Meetings in Winnipeg.

With current agreements set to conclude in March 2027, CORD is asking provincial and territorial ministers to jointly endorse the continuation of the federal commitment of \$500 million annually and work with the federal government and patient community toward renewed, predictable, multi-year funding.

The first three years have provided a strong foundation. Phase 2 is an opportunity to sustain access to innovative medicines while strengthening the diagnosis, care, services and monitoring that patients need to benefit from them.

We hope you will consider this letter and its accompanying examples of progress and innovation across Canada. CORD and our patient organization partners stand ready to contribute to this next phase.

Sincerely,



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President and CEO
Canadian Organization for Rare Disorders
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Encl.: Appendix A: Examples of Provincial and Interprovincial Progress, Innovation and Collaboration

Appendix A

Examples of Provincial and Interprovincial Progress, Innovation and Collaboration

October 2026

Introduction

Since the launch of Canada's National Strategy for Drugs for Rare Diseases in 2023, provinces and territories have undertaken a range of initiatives to improve access to medicines, diagnosis, specialized services and care for people living with rare diseases.

Some have been supported directly through the federal-provincial-territorial bilateral agreements. Others represent provincial investments, existing programs that have been expanded, collaborations among jurisdictions and healthcare partners, or exceptional responses to individual patient needs.

These examples illustrate the ways governments and their partners are already moving beyond funding individual medicines to strengthen the services and capabilities that make effective treatment and care possible.

The information has been assembled from Health Canada's published results, provincial government announcements, healthcare organizations, public reports and documented patient experiences. It is illustrative rather than comprehensive and does not represent a comparative assessment of provincial or territorial performance.

1. National Strategy for Drugs for Rare Diseases — Initial Results

Health Canada's first annual report on implementation of the bilateral agreements, covering April 2024 to March 2025, provides evidence of early progress.

Among the reported achievements:

- More than 632 Canadians obtained new access to rare disease medicines through funding provided under the Strategy.
- Of the funds spent during the first year, 87% supported new or expanded access to rare disease medicines outside the common list, reflecting provincial and territorial decisions about additional treatment needs.
- Approximately \$9.7 million was invested in improved screening and diagnostic capacity, including equipment, laboratory networks, education and training.
- Jurisdictions reported initiatives to improve drug authorization processes, expand specialist capacity, support travel for treatment and improve coordination and monitoring.
- Examples included expansion of newborn screening, investments in domestic genomic sequencing capabilities and collaborative approaches to treatment assessment.

These results demonstrate the value of dedicated funding that enables jurisdictions to address both shared national priorities and their own populations' needs.

The federal report is an important starting point, although many initiatives are described in aggregate or without identification of the individual jurisdictions involved. Additional provincial and territorial accounts could provide a richer understanding of what has been accomplished and the lessons that can be shared.

Source: [Health Canada, Drugs for Rare Diseases Bilateral Agreements: Results, 2024–25.](#)

2. British Columbia — Exceptional Response to Nathan Hepburn's Treatment Needs

Nine-year-old Nathan Hepburn has a rare, life-threatening brain arteriovenous malformation (AVM). Despite treatment in Canada, his condition continued to deteriorate.

His mother, Natasha Hepburn, identified a specialist in Germany offering a treatment approach not available to Nathan in North America. With community support and crowdfunding, the family financed two procedures, which demonstrated encouraging clinical progress, including a substantial reduction in the AVM.

Following an initial refusal of provincial funding, the BC government reconsidered its decision. In October 2026, then-Health Minister Ravi Kahlon approved exceptional funding of \$400,000 for Nathan's remaining treatment procedures in Germany.

Significance: The province's response demonstrates the importance of flexibility in addressing exceptional patient needs, especially when treatment expertise is unavailable in Canada. The case illustrates how new clinical evidence, patient and family advocacy, healthcare professional support and government responsiveness can contribute to a positive decision.

It also offers lessons for future approaches to evaluating and supporting exceptional treatment needs.

Sources: CityNews Vancouver, August 27 and October 3, 2026; family and clinical information shared with CORD.

3. British Columbia — Developing a Diagnosis-to-Therapy Pathway for Rare Genetic Diseases

In September 2026, British Columbia announced a partnership involving the Provincial Health Services Authority, BC Children's Hospital, the University of British Columbia and McGill University to develop a pathway from genetic diagnosis to potential personalized therapy.

The initiative was motivated by the experience of Gurmoh Gill, a child living with hereditary spastic paraplegia type 4.

In addition to supporting the development of a potential individualized gene-editing treatment, the partnership aims to establish processes that could help other patients and families navigate from diagnosis to assessment of possible therapeutic options.

Significance: This initiative demonstrates how a response to one patient's unmet needs can be used to build broader research, clinical and delivery capabilities for future patients. It also illustrates an emerging approach to preparing healthcare systems for highly personalized therapies.

Source: Government of British Columbia, *Advancing Treatment for Children with Rare Genetic Diseases*, September 19, 2026.

4. Alberta — Consultation and Planning for a Provincial Rare Disease Approach

On August 5, 2026, the Government of Alberta convened its first Rare Disease Summit, bringing together 44 participants from government, health agencies, patient and caregiver communities, clinical practice, research, industry and advocacy organizations.

The consultation explored opportunities to strengthen rare disease care, including:

- Earlier diagnosis and expanded screening.
- Timely access to medicines, specialists and other services.
- Improved patient navigation and coordinated care pathways.
- Better connections among research, data, clinical practice and patient outcomes.
- Continued collaboration among patients, healthcare providers, researchers, industry and governments.

The government's subsequent *What We Heard* report documented these priorities and identified opportunities for ongoing engagement.

Alberta has also identified investments in diagnostic imaging and screening capacity for rare diseases through its bilateral agreement.

Significance: Alberta's approach demonstrates the value of bringing together diverse partners to consider rare disease needs across the patient journey, rather than focusing exclusively on individual therapies.

The consultation represents an important foundation for further provincial planning, implementation and collaboration.

Sources: Government of Alberta, *Rare Disease Summit: What We Heard Summary*, August 5, 2026; Government of Alberta, *Rare Disease Summit: Background Information*; Canada–Alberta Rare Disease Funding Agreement.

5. Quebec — Provincial Rare Disease Policy and Clinical Navigation

Quebec's Rare Disease Policy and 2023–2027 Action Plan provide a framework addressing diagnosis, clinical expertise, coordinated services and access to treatment.

In January 2026, Quebec announced NAVI-NAT, a clinical navigation network designed to improve referrals for people with suspected but undiagnosed rare diseases.

The network builds on six designated interdisciplinary rare disease referral centres, with coordination of pediatric and adult services through CHU Sainte-Justine and the Centre hospitalier de l'Université de Montréal.

Significance: Quebec demonstrates how provincial policy can support the organization of clinical expertise and more coordinated pathways for people living with rare diseases.

NAVI-NAT offers a particularly relevant example of strengthening the link between suspected diagnosis, appropriate specialist referral and subsequent care.

Source: Government of Quebec, *Mise en place d'un réseau national de navigation clinique en maladies rares*, January 19, 2026.

6. Nova Scotia, New Brunswick and Prince Edward Island — Shared Newborn Screening for SMA

In August 2024, the Maritime Newborn Screening Program expanded to include spinal muscular atrophy (SMA), providing newborns across the three Maritime provinces with access to early screening for this treatable genetic condition.

The expansion was supported by approximately \$300,000 in provincial funding from Nova Scotia and \$420,000 from Muscular Dystrophy Canada for equipment, training and validation.

The program is operated through IWK Health and serves newborns in Nova Scotia, New Brunswick and Prince Edward Island.

Significance: This initiative demonstrates the value of interprovincial service delivery and partnerships among governments, healthcare institutions and non-governmental organizations. It also highlights how early detection can improve the opportunity for effective treatment before irreversible disease progression.

Source: IWK Health, *Newborns Now Screened for Spinal Muscular Atrophy*, August 20, 2024.

7. Saskatchewan — Expanding Genetics and Metabolics Services

Saskatchewan's 2026–27 provincial health budget includes increased funding for its Genetics and Metabolics Program.

The investment is intended to strengthen diagnostic and treatment pathways for individuals and families affected by rare or complex health conditions.

Significance: Saskatchewan's investment recognizes that improvements in treatment access require corresponding investments in specialist expertise, diagnostic capacity and coordinated clinical services.

It illustrates the value of strengthening existing healthcare infrastructure to address rare disease needs.

Source: Government of Saskatchewan, *2026–27 Health Budget*, March 18, 2026.

8. Ontario — Expanding Newborn Screening for X-linked Adrenoleukodystrophy

Ontario initiated newborn screening for X-linked adrenoleukodystrophy (XALD) through a pilot in March 2025, with expansion into routine screening planned for later that year.

Early detection allows children at risk of severe complications to receive specialist assessment, monitoring and, where appropriate, timely treatment.

Significance: This initiative demonstrates the need to connect new screening technologies with specialist follow-up and long-term clinical management.

It is an example of how earlier diagnosis can support more effective use of available interventions and potentially prevent serious disability.

Source: Newborn Screening Ontario, *Screening for X-linked Adrenoleukodystrophy*, 2025.

The examples above reflect information available as of October 2026. Initiatives vary in maturity, available outcome evidence and relationship to federal funding. Their inclusion does not imply that all have been completed or formally evaluated.

Building on Progress Across Canada

These examples demonstrate the diverse and complementary ways provincial and territorial governments are responding to rare disease needs. They include expanded access to medicines, improved screening and diagnosis, investment in specialized clinical services, interprovincial collaboration, strategic consultation and exceptional responses to individual patient circumstances.

They also demonstrate that important achievements are taking place both within and beyond the National Strategy for Drugs for Rare Diseases.

While federal reporting provides an essential account of the Strategy's implementation, there is considerable value in recognizing the specific initiatives and innovations developed by individual jurisdictions and their partners.

CORD would welcome additional examples and information from provincial and territorial ministries to provide a fuller account of the advances being made, the partnerships supporting them and the lessons that could benefit patients in other jurisdictions.

Together, these achievements provide a valuable foundation for Phase 2: sustaining timely access to innovative medicines while strengthening the diagnosis, care, services and monitoring needed to achieve the greatest benefit for patients.

The progress achieved during the first three years offers both a reason to continue the investment and an opportunity to accomplish even more through collaboration across Canada.