Canadian Organization for Rare Disorders

VIA EMAIL TO FIRST MINISTERS OF CANADA AND THE COUNCIL OF THE FEDERATION

July 21, 2026

Council of the Federation
Suite 630, 360 Albert Street
Ottawa, Ontario, K1R 7X7

Prime Minister's Office
80 Wellington Street
Ottawa, ON K1A 0A2

Re: Renew and expand the National Strategy for Drugs for Rare Diseases

Dear First Ministers,

Canada's first National Strategy for Drugs for Rare Diseases is demonstrating what sustained federal, provincial and territorial collaboration can achieve. Through an investment of up to $1.5 billion and bilateral agreements with every province and territory, the Strategy has accelerated access to innovative medicines and stimulated jurisdictions to invest in screening, diagnosis, data, evidence generation and patient-outcome monitoring.

Patients are already benefiting. Dedicated federal funding has enabled provinces and territories to provide new or enhanced access to rare disease treatments without waiting through the months or years often required to identify additional funding. Provincial and territorial governments are also committing resources and developing plans to build the diagnostic, clinical, data and monitoring capacity needed to improve outcomes over the longer term.

Canada now has an opportunity to build on this progress and assume a global leadership role.

In 2025, World Health Organization Member States adopted the first-ever World Health Assembly resolution recognizing rare diseases as a global health priority and calling for national action on diagnosis, care, research, innovation and treatment access. As countries begin implementing this commitment, **Canada is positioned to be a global leader**, helping to shape the international agenda and contributing as a full and influential partner in rare disease research, clinical trials and care networks.

The Strategy's benefits extend well beyond the medicines funded through bilateral agreements. It is helping Canada build capacity in **genomics-based research and diagnosis**, rare disease clinical trials, real-world evidence, data and monitoring, and cell and gene therapy development. These investments create knowledge, infrastructure and highly skilled expertise that can benefit patients across provincial and territorial boundaries and strengthen precision medicine throughout the Canadian health system.

The National Strategy is also enabling greater provincial and territorial coordination and collaboration. By bringing jurisdictions together around common priorities, shared evidence and complementary investments, Canada can make better use of limited specialist expertise, patient populations, data and infrastructure. This national foundation also allows Canadian researchers, clinicians and patients to participate more fully in international networks with Europe, the United States and other global partners.

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Behind this national opportunity are individual patients and families. A child's chance of receiving an early diagnosis or timely treatment should not depend upon where that child lives. Families should not have to appeal, fundraise or relocate because expertise or treatment is unavailable in their province or territory. Phase 1 is beginning to reduce these barriers; this progress must now be sustained and expanded.

With current bilateral agreements ending March 31, 2027, we urge First Ministers to commit now to a seamless and strengthened Phase 2.

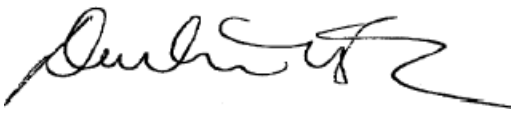
Specifically, CORD calls upon governments to:

- confirm sustained federal funding of up to $500 million annually and conclude successor agreements before the current agreements expire;
- protect continuity of treatment for patients already benefiting from the Strategy;
- expand investment in diagnosis, genomics, clinical capacity, coordinated care, data, real-world evidence and long-term follow-up; and
- engage patients, clinicians and rare disease organizations as partners in designing, implementing and evaluating Phase 2.

Canada has made an important strategic investment. Patients are already benefiting, and provinces and territories are committing to building the systems required for better outcomes. This is not the time to pause or rebuild from the beginning. It is the time to secure, strengthen and scale what Canada has started.

By acting together, First Ministers can improve the lives of Canadians living with rare diseases while establishing Canada as a global leader and a trusted, influential partner in the future of diagnosis, research, clinical trials and precision medicine.

Sincerely,



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