



Canadian Organization  
for Rare Disorders

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January 14, 2025

The Right Honourable Justin Trudeau, P.C., M.P., Prime Minister of Canada  
The Honourable Pierre Poilievre, P.C., M.P., Leader of the Official Opposition and  
Conservative Party of Canada  
M. Yves-François Blanchet, M.P., Leader of the Bloc Québécois  
Mr. Jagmeet Singh, M.P., Leader of the New Democratic Party of Canada  
Ms. Elizabeth May, M.P., Leader of the Green Party of Canada

Federal party leaders of the Government of Canada,

**Subject: Canada's Rare Disease Strategy is needed NOW more than ever**

Imagine life in Canada without a Cancer Control Strategy, a Diabetes Strategy, a Heart Health Strategy, or a Mental Health Strategy. Imagine the millions who would be suffering debilitating illnesses, filling hospital beds, dropping out of the workforce to seek care or to give care, and dying prematurely from preventable or treatable causes? Undoubtedly, we are grateful for our fellow citizens who have benefitted from these public health strategies.

So, WHY, is Canada the ONLY developed country that does not have a government-endorsed strategy to address RARE DISEASE, a devastating public health issue affecting over 3 million Canadians, more than the number affected by all types of cancer combined or the number diagnosed with diabetes or cardiovascular disease.

Almost a decade ago to the day – on the cusp of the 2015 election – the Canadian Organization for Rare Disorders (CORD) wrote to the leaders of Canada's political parties to solicit support for the community-led Canada's Rare Disease Strategy. We pointed to the urgent need for action. While each rare disease affects only a few people, collectively the 6,000+ conditions constitute a significant public health issue, directly affecting 1 in 12 Canadians, about 3 million in total, 70% of whom are children. Most rare diseases are progressive, debilitating, or life-threatening and only 5% have approved therapies. Because the number of persons affected with each disease is so small, a national approach is essential. A decade ago, when CORD proposed a Rare Disease Strategy, Canada was the only developed country worldwide that did not have a national plan for rare disease. It is unconscionable that in 2025, as we embark on another federal election, Canada still does not have a national rare disease strategy.

In March 2023, the federal government announced \$1.5 billion over three years for a National Rare Disease *Drug* Strategy, with \$32 million for research and \$20 million to



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improve data collection. The majority, \$1.4 billion goes to the provinces through bilateral agreements; however, there is little guidance to assure the monies will have maximum benefit for patients and optimal value for health systems and the governments. According to the terms of signed agreements, provinces need cover only one drug from a “common list” of 12 drugs in the first two years, and by Year 3, assume only 10% of the funding for drugs on the common list, with federal funds covering the remaining 90%. Moreover, monies saved from provincial drug budgets do not need to be re-directed to other rare disease services. Sadly, there is high probability that the \$1.4 billion will result in very little net sustainable benefit for persons living with rare disease and their families, unless governments take a different course of action now.

Ten years after CORD brought Canada’s Rare Disease Strategy to Parliament, we are once again calling upon the federal political leaders to prioritize a National Rare Disease Strategy and to support the development of provincial rare disease plans that will ensure funding from the Rare Disease Drug Strategy has optimal sustainable impact. The patient, health professional, and private sectors have been highly active over this decade. Healthcare professionals will now be able to coordinate care and research under the new Canadian Rare Disease Network (<https://canadianrdn.ca>); the patient community, with leadership from CORD, is engaged in all areas from research and clinical trials to registries and evidence development; and advances in genetics, digital technology and new therapeutics are creating unprecedented opportunities for rare disease diagnosis, treatment, and prevention.

The time is now for Canada to catch up with and surpass the rest of the world with national, provincial, and local programs for rare disorders. As we head into another election cycle, we recognize that 2025 is not just like 2015 for rare disorders. Indeed, it will be much worse if we squander the opportunity to invest our financial and human capital resources in coordinated and sustainable initiatives focused on the overriding goal of improving the lives of Canadians.

**We are counting on your support and leadership as the next federal government or as an important player in the House of Commons to help make the Strategy a reality. We invite you to respond to the questions outlined below. We will be circulating your responses to the rare disease community and will be posting them on our website at [www.raredisorders.ca](http://www.raredisorders.ca).**

### **Question 1**

*Should your party form the next Government, how will you provide federal leadership and collaborate with provincial and territorial governments and stakeholders to improve the health outcomes of the nearly 3 million Canadians living with a rare disease?*



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**Question 2**

*Should your party form the next Government, will you support Canada's Rare Disease Strategy and its five goals of improving early detection and prevention, getting the right care to patients as early as possible, enhancing community support, providing sustainable access to promising therapies, and promoting innovative research? See:*

*[https://www.raredisorders.ca/uploads/Documents/CORD\\_Canada\\_RD\\_Strategy\\_22May15.pdf](https://www.raredisorders.ca/uploads/Documents/CORD_Canada_RD_Strategy_22May15.pdf)*

**Question 3**

*Should your party form the next Government, will you move quickly to introduce regulations to make the orphan drug regulatory framework a reality?*

Sincerely,

A handwritten signature in black ink, appearing to read 'Durhane Wong-Rieger', with a stylized flourish at the end.

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