***VIA COURIER/EMAIL***

NAME

DATE

ADDRESS

Dear xx

**Subject: The [Conservative Party of Canada / New Democratic Party of Canada / Liberal Party of Canada / Green Party of Canada]’s support for Canadians living with rare diseases and Canada’s Rare Disease Strategy**

In the context of the upcoming federal election, the Canadian Organization for Rare Disorders (CORD), Canada’s national network of rare disease organizations, is interested in finding out how **[INSERT PARTY NAME] will take action to improve the lives of the nearly 3 million Canadians with rare diseases and their families.**

 **“Rare diseases” is one of Canada’s biggest public health challenges**, on par with diabetes (affecting 2.4 million Canadians) and cancer (combined affecting about 1.4 million persons). In fact, the percentage of Canadians with rare diseases is about the same as the number at risk for mental illness (i.e., 8%). One key difference is that **about half of those with rare diseases are children**. Another important difference is that patients with rare diseases do not get the same level of care and treatment as other Canadian patients. They face more **unnecessary delays in testing, wrong diagnoses and missed opportunities to effectively treat.** These challenges not only negatively impact the health and quality of life of these patients and their caregivers, but they are also very costly for the healthcare system and Canadian society.

This is why CORD recently launched **Canada’s Rare Disease Strategy,** whichlays out a five-point action plan calling upon all levels of government to participate to:

* Improve early detection and prevention
* Get the right care to patients as early as possible
* Enhance community support
* Provide sustainable access to promising therapies and
* Promote innovative research.

Implementing this Strategy will help bring our country in line with the vast majority of other developed countries that have already adopted national plans to improve the health of patients with rare diseases. Domestically, we have also already implemented national plans or strategies for diabetes, cancer and mental illness. **Canada now needs to do the same for people suffering from rare diseases.**

**The federal government has an important role to play in helping implement this Strategy, especially with regard to rare disease research, establishment of rare disease centers of excellence and implementation of a federal orphan drug regulatory framework.** Regarding the latter issue, we understand that draft regulations have already been developed by federal officials and are ready to be published. We ask for your cooperation and leadership to ensure that these regulations get adopted as quickly as possible to help facilitate patient access to much needed new rare disease therapies in Canada.

**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.com.**

**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?*

**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?*

**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,

(SIGNATURE)

(CONTACT INFO)

**Attachments:** Canada’s Rare Disease Strategy (English – French version will be available shortly at [www.raredisorders.ca](http://www.raredisorders.ca))

Executive Summary of the Strategy (English and French)