

April 28, 2020

Minister of Health
Federal, Provincial, and Territorial

Dear Minister of Health,

The Canadian Organization for Rare Disorders is Canada's national association of over 100 rare disease patient organizations, representing approximately 2.8 million Canadians affected by rare diseases. Firstly, I would like to state without reservation that CORD joins with all Canadians in the fight against COVID-19 and strongly supports the federal and provincial/territorial government actions to protect and treat all Canadians during this pandemic.

However, CORD also wants to raise to your attention to a serious unintended consequence of the pandemic responses, which is now threatening the lives and wellbeing of another cohort of Canadians, those living with chronic conditions, both rare and common. Patients with underlying conditions that compromise the immune, respiratory, and cardiac systems are more susceptible to COVID-19 and its complications.

In early April CORD sent out a survey asking the impact of COVID-19 on rare disease patients and families. We were shocked by the extent to which access to healthcare and other services was affected and the seriousness of the consequences. We are attaching a summary of the impact based on the initial 300 responses. In brief, one-half of respondents had experienced difficulty receiving medical care, such as delayed or cancelled surgeries, bloodwork, dialysis, and physiotherapy. Over two-thirds were concerned about seeking healthcare because of fear of contracting COVID-19. Almost half could not access rehabilitation or critical services, including personal support care. About 40% could not access their prescribed medications, not because of drug shortages, but because of logistical issues in healthcare or pharmacy services or response to special access requests,

In a separate survey sent to the pharmaceutical suppliers of rare disease medicines, CORD received assurances that Canadian drug supplies were not in jeopardy and that steps were being taken to meet future needs, to provide alternative treatment sites and to continue clinical trials.

CORD strongly supports the concerted actions that government and health system are taking in the fight against COVID-19. However, it is equally vital that we do not neglect essential care and treatment for patients with existing health conditions. Unfortunately, the feedback from our rare disease patient survey paints a stark and disconcerting picture of limited, delayed, and denied testing, medical services, surgeries, rehabilitation therapy, supportive care, and medicines, all of which inevitably put patient lives and wellbeing at risk. Our public health

experts tell us that this is most likely the first of two or three waves and that the impact of COVID-19 will be felt until 2021. This will have a profound effect on patients with rare diseases.

Our summary report identifies key learnings from the COVID-19 crisis that would improve rare disease patient outcomes and experience, and, as importantly, the experience of the healthcare providers. These are:

BIG Learning 1. You gotta have a plan. Every rare disease patient needs to have an individualized plan developed in consultation with the patient and family and readily available (in electronic form), to all providing healthcare services, especially in emergency situations.

BIG Learning 2. Rare disease is a distinct medical speciality. Like oncology, cardiology, neurology, endocrinology, and pediatrics, rare disease needs comprehensive specialty centres networked to localized practitioners and community-based services.

BIG Learning 3. Deal with the crisis, but don't sacrifice those with other healthcare needs. Set up a team to identify, prioritize, triage, and alternatively resolve the needs of those with chronic and other healthcare conditions.

BIG Learning 4: Canada needs an innovative pharmaceutical industry. Companies in Canada are stepping up to assure adequate supplies of emergency drugs and medical devices and are partnering with researchers to develop new tests, therapies, and vaccines for COVID-19. At the same time, they are ensuring that Canadians with rare and common conditions have continued access to the drugs, tests, and other technologies needed. Perhaps this is the opportunity to develop truly effective public-private partnerships.

The problems experienced by rare disease patients and families were not directly caused by COVID-19. Sadly, it has taken a pandemic to bring pervasive deficiencies and dysfunctions in our healthcare system to the surface. We urge governments to address these issues now. As a patient community, we are ready and capable of helping generate and implement changes to serve all Canadians ... before the next COVID-19 wave or another health crisis.



Durhane Wong-Rieger, PhD
President & CEO
Canadian Organization for Rare Disorders
151 Bloor St W, Suite 600
Toronto, ON M5S 1S4
durhane@raredisorders.ca
www.raredisorders.ca