

Federal Minister of Health Response to our COVID-19 Impact on Rare Disease Patients Letter

May 19, 2020 (response sent by email)

Dear Dr. Wong-Rieger,

Thank you for your email dated April 28, 2020, addressed to the Honourable Patty Hajdu, the Minister of Health. We would like to thank you for taking the time to express the concerns of the Canadian Organization for Rare Disorders (CORD) amid the current COVID-19 outbreak. We sympathize with the challenges that Canadians with rare diseases face during this public health emergency.

Protecting the health and safety of Canadians is our top priority.

A Cabinet committee on COVID-19 has been established to ensure whole-of-government leadership, coordination, and preparedness for a response to the health and economic impacts of the virus. This includes coordination of efforts with provincial and territorial counterparts.

The Committee will build upon the measures already taken by the Government of Canada to limit the spread of the virus, and to make sure we are protecting the health and safety of all Canadians.

We regret to hear that survey respondents had difficulty receiving medical care and other healthcare services. In Canada, the provinces and territories are responsible for the design, delivery and management of health care in their jurisdictions, including addressing issues like the ones you have raised, such as delays in receiving medical care. If you have not already done so, you may wish to share your concerns with the provincial Ministers of Health as they are in a better position to address your concerns and offer more specific information about efforts to provide timely access to quality care in the provinces.

With respect to access to medicines, the outbreak has strained the global supply chain of pharmaceuticals and resulted in an unprecedented demand for access to certain drugs. That is why in many provinces, directives have been issued to dispensers to limit the quantity of prescription medication to a month supply in an effort to conserve the drug supply and ensure that sufficient medication will be available for all provincial residents.

With respect to clinical trials, we are aware that some trials were put on hold either because conducting the trial during the pandemic would have put patients' safety at risk or because hospitals needed to reassign resources to other areas. However, Health Canada did issue a Notice to clinical trial sponsors outlining some flexibilities that could be implemented to allow clinical trials to continue where possible.

We are surprised to hear about difficulty reaching the Special Access Programme (SAP). The SAP has maintained normal operations throughout the pandemic during both regular working hours (8:30-4:30 EST) and after hours, weekends and holidays. The programme

continues to receive and process requests in the usual way and has dealt with a myriad of drug access issues caused by or complicated by the pandemic. Practitioners / pharmacists wishing to reach the programme can call (613) 941-2108 or email at hc.sapd-pasm.sc@canada.ca

Additionally, we know that for many Canadians who require high-cost prescription drugs to treat rare diseases, the cost of these necessary medications can be astronomically high. Accordingly, as part of Budget 2019, the Government of Canada proposes to invest \$1 billion over two years, starting in 2022-23, with up to \$500 million per year ongoing, to develop a national strategy for high-cost drugs for rare diseases. This will enable Canadians to achieve better access to the effective treatments they need.

In the meantime, we will continue to work with provinces, territories, and other partners to improve the accessibility and affordability of medications.

Thank you for taking the time to write, letters like yours help us to better understand the concerns of Canadians.

Yours sincerely,

Strategic Policy Branch
Health Canada