



Canadian Organization
for Rare Disorders

APPLYING LESSONS FROM COVID-19 TO BETTER HEALTHCARE FOR RARE DISEASES

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INTRODUCTION

The Canadian Organization for Rare Disorders joins with all Canadians in the fight against COVID-19. But for Canadians with chronic conditions, rare and common, the fight against their disease has become even more challenging. 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. Approximately, 300 responses have been received.

IMPACT OF COVID-19

- **3/4 feel at “great” or “very great” risk for COVID-19 complications**

“My daughter gets every virus and takes longer to recover.”

- **2/3 feel “somewhat” to “very” concerned about seeking healthcare--fear of exposure to COVID-19**

“I've been told should I contract COVID-19 I would be low on the list for treatment due to shortage.”

- **1/2 had difficulty receiving medical care, delayed/cancelled surgeries, bloodwork, dialysis, therapy.**

“The surgery not happening would resolve a problem; meantime I am not functional, am bedridden and in a lot of pain.”

- **1/2 had difficulty accessing rehabilitation or critical services, including personal support care.**

“House Bound/extreme mobility issues/no one able to help because of mine and their fears/stay at home in effect.”

- **40% experience “some” to “great” difficulty getting access to medicines**

“System delays e.g. cancellation of clinical trial, delayed Health Canada approval for a Special Access Program request, and inability to access bloodwork to qualify for therapy.”

- **3/4 of experienced “some” to “great” anxiety, fear or stress; 1/2 had withdrawn emotionally**

“very high stress, parent of 4 children, two of whom have specialized needs, panic attacks, deeply struck with grief and anxiety on daily basis.”

PHARMACEUTICAL INDUSTRY RESPONSE

Survey sent to the pharmaceutical suppliers of rare disease medicines

- Most Canadian drug supplies not in jeopardy
- Taking steps to assure procurement, production, and delivery to meet future needs
- Making alternative arrangements for drug administration (for example, at specialty pharmacy sites)

or supporting home administration

- On-going clinical trials not interrupted, with alternative arrangements for administration, monitoring and follow-up data collection if necessary



BIG LEARNING FROM FEEDBACK ON COVID-19 IMPACT ON RARE DISEASE

CORD strongly supports actions in fight against COVID-19.

Equally vital not neglect essential care and treatment for patients with existing health conditions.



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.

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.

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.

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.

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