FIGHT FOR OUR LIVES

Dear Prime Minister Trudeau, premiers and Canadian health ministers,

Patients are out of patience. And rightly so.

Five years ago, the federal government committed $1 billion to set up a National Rare Disease Drug Strategy. The Canadian Organization for Rare Disorders expressed appreciation ... but remained "guardedly hopeful." Hopeful that this was not just another promise. After four years, our hope had nearly dissolved into despair. Last year, the federal government launched the National Strategy for Drugs for Rare Diseases, with $1.4 billion to be allocated through federal-provincial bilateral agreements.

There is no sense of urgency, no goals to treat patients as soon as possible, no timelines for expending the $1.4 billion, and, most grievously, no inclusion of patients and healthcare providers in the negotiations.

Today, five years after the federal commitment, not a single rare disease patient has received a single penny to help fund a rare disease drug.

As former Ontario ombudsman André Marin said twenty years ago on another rare disease issue – newborn screening – patients have the right to be impatient. Morin called out the "...consequence of politicians and bureaucrats failing to sense the urgency and ... to remedy the situation ..."

Time is Up! Rare disease patients cannot afford to be patient any longer.

Meanwhile, federal, provincial and territorial governments are funding only a fraction of the rare disease medicines available in the European Union and the United States.

With one child dying with a rare disease in Canada every 18 minutes and Canadians of all ages dealing with years before diagnosis or access to new therapies, our lives are on the line, and nothing is more urgent.

The rare disease community will continue to lead, despite government inaction, building on the community-led Canadian Rare Disease Strategy of 2015. This year we're launching the Canadian Rare Disease Network to provide collaborative and networked care for all patients no matter where they live in Canada.

We need you more than ever to act with urgency, with more than promises:

- Federal government funding for new medicines can happen tomorrow – we know which therapies are "languishing in bureaucracy" – so move forward immediately on the promised funding of rare disease drugs
- Provincial governments need to follow Quebec's lead and implement rare disease strategies and demand that Ottawa invest the long-promised funding for medicines

Rare disease patients – along with our clinicians and caregivers – are right to be impatient after all these years.

We need you to join us in this #FightForOurLives.

Sincerely,

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