



November 26, 2015

The Honourable Dr. Jane Philpott, PC MP
Minister of Health
70 Colombine Driveway
Tunney's Pasture

Postal Location:
0906C Ottawa, Ontario
K1A 0K9

Subject: Outstanding Federal Government Commitments to Canadians with Rare Diseases

Dear Minister Philpott,

The Canadian Organization for Rare Disorders greets with optimism your appointment as the federal point person with the mandate to enable each and every Canadian to have access to quality, efficient, and sustainable healthcare. There are two outstanding commitments made by your predecessors that could lead to life-altering benefit for the nearly 3 million Canadians living with rare diseases.

Of the 7,000 rare diseases, only 5% have any effective treatments. Canadian patients access only about 60% of these, due in part to the lack of a national Orphan Drug regulatory framework, which supports research, development, clinical trials and commercialization of treatments. In October 2012, Federal Health Minister Aglukkaq committed to establishing a Canadian Orphan Drug Framework, similar to the 1983 USA Orphan Drug Act and the 2000 European Union Orphan Drug Act. The relevant regulations and departmental guidances are fully prepared but were never implemented. We urge you to implement Canada's Orphan Drug Framework without further delay.

Second, in October 2005, Health Minister Ujjal Dosanjh committed to patients and families, who had waited for two days outside the Federal/Provincial/Territorial Health Ministers meeting, to develop a plan for funding (expensive) drugs for rare diseases. Eleven years later, these patients are still waiting. CORD is committed to working with the federal and provincial governments to achieve rational and sustainable solutions that would provide appropriate and timely access to patients who are suffering from progressive and life-threatening rare conditions. We urge you to work collaboratively with the Provincial and Territorial Health Ministers who have committed to considering a plan at the next joint meeting in January 2016 in Vancouver.

Finally, to show your commitment to helping many of Canada's most vulnerable citizens, we need your support for Canada's Rare Disease Strategy and a new Canadian Partnership for Rare Diseases. We ask to meet with you at the earliest opportunity to discuss the opportunities for finding solutions for 2.8 million Canadians suffering from rare diseases. In the meantime, please visit <http://www.raredisorders.ca/canadas-rare-disease-strategy/> to learn more about the role of the federal government in implementing the strategy, and how many Canadians - patients, researchers, healthcare professionals, health charities and the private sector - are ready to do their part.

Sincerely,

A handwritten signature in black ink, appearing to read 'Durhane Wong-Rieger', with a stylized flourish at the end.

Durhane Wong-Rieger
President & CEO
Canadian Organization for Rare Disorders