



January 14, 2016

The Honourable Jane Philpott
Minister of Health
70 Colombine Driveway,
Tunney's Pasture
Postal Location: 0906C
Ottawa, Ontario K1A 0K9

Honourable Minister,

On behalf of the Network of Rare Blood Disorder Organizations (NRBDO), I am writing in support of [Canada's Rare Disease Strategy](#), as developed by COD. Specifically, we are requesting the timely implementation of a national orphan drug regulatory framework and the adequate funding of drugs for rare diseases.

Every Canadian deserves access to quality, efficient, and sustainable healthcare. 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, then 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.

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. 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 Vancouver at the end of this month.

The NRBDO, with its member organizations and the patients we represent, look forward to working with the federal and provincial governments to achieve sustainable solutions that provide timely access to life-saving treatments for those living with rare disorders.

Sincerely,

A handwritten signature in black ink, appearing to read "W. Sauve", with a horizontal line extending to the right.

Wendy Sauve
Chairperson

Network of Rare Blood Disorder Organizations (NRBDO)/Réseau des Associations Vouées aux Troubles Sanguins Rares (RAVTSR)