



June 23, 2022

Hon. Jean Duclos
Minister of Health
hcminister.ministresc@hc-sc.gc.ca

Re: Canada's National Strategy for Drugs for Rare Diseases

Dear Minister Duclos,

I am writing today regarding the National Strategy for Drugs for Rare Diseases, with concerns from the rare blood and bleeding disorder community that have not yet been addressed during consultations.

The Network of Rare Blood Disorder Organizations (NRBDO) is a pan-Canadian coalition of fifteen not-for-profit patient organizations representing people with rare blood and bleeding disorders and/or people with chronic conditions who are recipients of blood or blood products or their alternatives. Together, we represent thousands of patients and have had a vested interest in timely and equitable access to novel therapies for patients in Canada since our formation in 2004.

We are very interested in Health Canada's work in developing a National Strategy for Rare Diseases, both in ensuring that our current access through Canadian Blood Services and Héma-Québec formularies is not compromised, while also considering the opportunity for improved access to therapies along with clinical trials, data collection, and research and development in Canada. In particular, novel therapies that replace blood products are a growing area with a less clear path to timely and equitable patient access.

Despite participation in the consultation process, including asking plainly during the April 26, 2022 Stakeholder Roundtable Session with Health Canada how blood products and their alternatives are being considered, we are disappointed to have received zero information on how the needs of this portion of the rare disease community are being incorporated into the National Strategy.

The NRBDO is committed to ensuring that the patient voice be heard. We fully support the development of a National Rare Disease Strategy, and we are requesting a meeting with you and/or members of your policy staff to discuss how blood products and their alternatives are being incorporated.

Many thanks,

A handwritten signature in black ink that reads 'Jennifer van Gennip'.

Jennifer van Gennip
Executive Director, NRBDO