

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

March 18, 2019

Hon. Sarah Hoffman Hon. Adrian Dix	Minister of Health, Alberta Minister of Health, British Columbia
Hon. Cameron Friesen	Minister of Health, Seniors and Active Living, Manitoba
Hon. Hugh J.A. Flemming	Minister of Health, New Brunswick
Hon. Dr. John Haggie	Minister of Health and Community Services, Newfoundland & Labrador
Hon. Glen Abernethy	Minister of Health and Social Services, Northwest Territories
Hon. Randy Delorey	Minister of Health and Wellness, Nova Scotia
Hon. George Hickes	Minister of Health, Nunavut
Hon. Christine Elliott	Minister of Health and Long-Term Care, Ontario
Hon. Robert Mitchell	Minister of Health and Wellness, Prince Edward Island
Hon. Danielle McCann	Minister of Health and Social Services, Quebec
Hon. Jim Reiter	Minister of Health, Saskatchewan
Hon. Pauline Frost	Minister of Health and Social Services, Yukon

Re: Consumer Representation on Canadian Blood Services Board of Directors

Dear Ministers,

I am writing today on behalf of the Network of Rare Blood Disorder Organizations (NRBDO) regarding consumer representation on the Canadian Blood Services (CBS) board.

Consumer representation, particularly by individuals connected to patient organizations, has several advantages:

- Those with experience on the consumer end of our blood system bring an important and unique perspective to the board;
- Concerns of recipients can be heard at the highest level of CBS; and
- The information raised through discussions of blood supply and safety can be easily shared with • patient organizations.

Given the important role that consumer representatives have as a liaison between patient organizations and CBS, it is with grave concern that we again note the recent appointment of two consumer representatives who are not actually consumers.

CBS bylaw states the consumer representatives must be chosen "based on their relevant knowledge and/or experience with organizations representing consumers of blood and blood products." Failure to do so erodes the transparency and trust in the blood system and deprives the board of an essential perspective.

> 36 Toronto St. Suite 1, Barrie ON L4N 1T9 | info@nrbdo.ca www.nrbdo.ca



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

The NRBDO is committed to ensuring the patient voice is heard, and strongly urges the Provincial/Territorial Ministers of Health to respect CBS bylaws they themselves created and name true consumer representatives to the CBS board at the first opportunity.

Sincerely,

Samlwak:

Gergana Sandeva, Chair Network of Rare Blood Disorder Organizations (NRBDO)

cc: Graham Sher, CEO of Canadian Blood Services Mel Cappe, Chair of CBS Board of Directors