



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

July 11, 2022

Hon. Jason Copping, Alberta  
Hon. Adrian Dix, British Columbia  
Hon. Audrey Gordon, Manitoba  
Hon. Dorothy Shephard, New Brunswick  
Hon. Dr. John Haggie, Newfoundland  
Hon. Julie Green, Northwest Territories  
Hon. Michelle Thompson, Nova Scotia  
Hon. John Main, Nunavut  
Hon. Sylvia Jones, Ontario  
Hon. Ernie Hudson, Prince Edward Island  
Hon. Paul Merriman, Saskatchewan  
Hon. Tracy-Anne McPhee, Yukon

Honourable Ministers,

Thank you for the response from Ontario to our letter of October 2021 regarding the reimbursement and distribution of all blood and plasma products on the Canadian Blood Services (CBS) formulary.

As a follow up, we'd like to raise another barrier to equitable access to plasma-derived treatments: the decision by the provinces and territories to not allow a product that is on a formulary in any jurisdiction within Canada to be considered for the CBS formulary.

Currently, if a plasma-derived therapy makes its way onto a provincial formulary, such as the augmentation therapy for Alpha-1 Antitrypsin Deficiency which is only approved for reimbursement in British Columbia, it is ineligible for consideration for reimbursement and distribution through CBS. This leaves patients in the rest of the country with no chance of receiving this life-saving treatment. The NRBDO's member organization, Alpha-1 Canada, has been fighting this policy for over five years. As policymakers consider this request, over fifty Alpha-1 patients have died a preventable death—twenty-seven in 2021 alone.

36 Toronto St. Suite 1, Barrie ON L4N 1T9 | [info@nrbd.ca](mailto:info@nrbd.ca)

[www.nrbd.ca](http://www.nrbd.ca)

As noted previously, the primary purpose for the NRBDO's insistence on distribution through CBS is to ensure equitable access to these therapies regardless of geographic or socio-economic status. Other benefits include timely access to novel therapies, improved vigilance, and better cost-management.

We are asking you to eliminate this unnecessary barrier to equitable healthcare, effective immediately.

The NRBDO is committed to working with governments and Canadian Blood Services to ensure equitable, timely, and reliable access to the safest and most efficacious therapies for patients living with rare blood disorders in Canada. We would be happy to meet with you at your convenience and introduce you to some patients currently impacted by this policy.

Sincerely,

A handwritten signature in cursive script that reads "Jennifer van Gennip".

Jennifer van Gennip  
Executive Director  
Network of Rare Blood Disorder Organizations (NRBDO)