



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

January 23, 2018

Dr. Graham Sher  
Chief Executive Officer  
Canadian Blood Services (CBS)  
1800 Alta Vista Drive  
Ottawa, ON K1G 4J5

Dear Dr. Sher,

On behalf of the Network of Rare Blood Disorder Organizations (NRBDO), I am writing today to share the request we are submitting to CADTH for a path for patient input on blood product reviews, and to ask that CBS support our request to CADTH.

In conversation with Mr. Bond ahead of this formal request, he suggested that the reason CADTH was not including patient input in reviews of blood products was because CBS had not asked them to. Considering the strong commitment CBS has to keeping the patients who use these blood products at the centre of your work, we trust you will see the value in asking CADTH to include patient input in blood product reviews.

The NRBDO is committed to ensuring the patient voice is heard, and working with governments, CBS and H-Q to ensure the availability of the best blood products for patients in Canada. We urge you to ask CADTH to include a call for patient input in their reviews of blood products, and have those submissions included in a meaningful way.

Sincerely,

A handwritten signature in black ink, appearing to read 'Whitney Goulstone'.

Whitney Goulstone  
Chair, NRBDO

*The Network of Rare Blood Disorder Organizations (NRBDO) is a coalition of national patient groups, formed to share the best practices in health care delivery for people with rare blood disorders such as hereditary angioedema; aplastic anemia, Fanconi anemia, paroxysmal nocturnal hemoglobinuria (PNH), and myelodysplasia; primary immune deficiency; porphyria, sickle cell disease, thalassemia, thrombotic thrombocytopenic purpura (TTP), hereditary hemorrhagic telangiectasia (HHT), hemophilia, and von Willebrand disease.*

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