



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

January 23, 2018

Mr. Ken Bond
Director, Patient Engagement and International Affairs
Canadian Agency for Drugs and Technologies in Health (CADTH)
865 Carling Ave, Suite 600
Ottawa, ON K1S 5S8

Dear Mr. Bond,

On behalf of the Network of Rare Blood Disorder Organizations (NRBDO), I am writing today to request a path for patient input in the review of blood products.

As you personally presented to us at our NRBDO forum in November 2016, patient input is important to CADTH because:

- HTA recommendations will ultimately affect patients for whom the technology is intended
- Only patients and their family/caregivers have
 - day-to-day lived experience with the disease or condition
 - direct experience with currently available treatments (if applicable) and possibly experience with the technology being reviewed
- Patients and their caregivers can provide their perspectives on the most important considerations and outcomes for a new technology

It seems obvious that the importance of patient input on drug reviews would carry over to 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 include a call for patient input in your reviews of blood products, and have those submissions included as a decision factor when determining your recommendations to CBS.

Sincerely,

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

Whitney Goulstone
Chair, NRBDO

cc: Dr. Graham Sher, Canadian Blood Services

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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