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,

Whitney Goulstone
Chair, NRBDO

cc: Dr. Graham Sher, Canadian Blood Services