



September 10, 2019

Dr. Graham Sher
Chief Executive Officer
Canadian Blood Services
1800 Alta Vista Drive
Ottawa, Ontario, K1G 4J5

Dr. Sher,

At the beginning of the summer, the NRBDO presented to the CBS Board of Directors on our expectations for patient engagement in new product reviews, following a string of frustrating delays impacting access to innovative and - in some cases - life-changing therapies for the patient groups we represent.

We quickly received a follow up letter from your Chair, Mel Cappe, thanking us for developing recommendations, assuring us of CBS's commitment to "keep patient and stakeholder engagement central in the development of an improved product selection process," and indicating we would be kept up to date in the weeks and months ahead.

With no further communication throughout the summer, we are reaching out to share our newly adopted Policy on Patient Engagement in Blood Product Reviews. We are also inviting representatives of CBS to our Fall Forum on Saturday, November 2nd, to discuss opportunities for and importance of patient engagement, and to share an update on your improved product review process.

We believe we are both interested in a review process that ensures patients living with rare blood disorders have timely access to innovative therapies, and that they continue to be distributed through CBS. We look forward to resuming discussions with you on what the review process will entail.

Sincerely,

Erin Harder
Acting Chair,
Network of Rare Blood Disorder Organizations (NRBDO)