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

June 5, 2018

Deputy Minister Milton Sussman, Alberta
Deputy Minister Stephen Brown, British Columbia
Deputy Minister Karen Herd, Manitoba
Deputy Minister Tom Maston, New Brunswick
Deputy Minister John Abbott, Newfoundland
Deputy Minister Bruce Cooper, Northwest Territories
Deputy Minister Denise Perret, Nova Scotia
Deputy Minister Colleen Stockley, Nunavut
Deputy Minister Bob Bell, Ontario
Deputy Minister Kim Critchley, Prince Edward Island
Deputy Minister Michel Fontaine, Quebec
Deputy Minister Max Hendricks, Saskatchewan
Deputy Minister Stephen Samis, Yukon

Deputy Ministers,

On behalf of the Network of Rare Blood Disorder Organizations (NRBDO), I am writing today to bring your attention to the need for an improved review process for new blood products. The current process is overly long and lacks patient input at some critical junctures. We are asking for this process to be streamlined, with greater transparency, and for an expedited review process option to be added.

Consistency

The distribution and reimbursement of the cost of blood products, including plasma protein products and their recombinant substitutes, has always occurred via Canadian Blood Services (CBS) and Héma-Québec. This has resulted in fair and equitable access to an optimal supply of these essential therapies to Canadians, without barriers to patient access due to cost, and it is the position of the NRBDO that this practice continues.

Patient Input

The NRBDO is committed to ensuring that the patient voice be heard, and was very disappointed when we learned that patient input would not be considered in an upcoming CADTH review of a new blood product for hemophilia patients. We were led to understand that CADTH is simply undertaking an economic analysis of the new drug and therefore patient input was not needed. On the contrary, we believe that patient organizations are well-placed to provide real-world evidence on utilization and cost. Indeed, for CADTH's non-blood product drug reviews, patient input is valued as patients are the context experts on the day-to-day impact of their condition or disease, and have lived experience with currently available therapies. It seems obvious that the importance of patient input on drug reviews would carry over to blood product reviews.

Transparency

Patient groups are growing increasingly frustrated with the lack of transparency with the Provincial/Territorial Blood Liaison Committee (P/T BLC). Requests for information about blood product access are often ignored, and meeting requests refused. On more than one occasion, our member patient groups have gone to CBS only to be told to take the issue to the P/T BLC, and then been told by the P/T BLC that CBS handles patient input. We would like to see greater transparency in the review process and the decisions impacting patient access to the blood products they rely on.

Expedited Review Process Option

Health Canada has an accelerated review process to evaluate promising new drugs for serious and unmet patient needs. This reduces the regulatory approval time by almost half. No expedited review process exists for decisions on reimbursement of such drugs by the provinces and territories. We therefore request that in Quebec l'INESSS and Héma-Québec, and in the rest of Canada, CBS, P/T BLC and CADTH develop expedited review processes to make decisions on the reimbursement of breakthrough drugs that meet serious, unmet patient needs.

The NRBDO is committed to working with governments, CBS, and Héma-Québec to ensure timely access to the safest and most efficacious blood products for patients in Canada. We plan to raise these same requests at the CBS Open Board meeting on June 27th.

Sincerely,

Gergana Sandeva
Chair, NRBDO