NRBDO RAVTSR

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

August 14, 2017

Honourable Adrian Dix
Minister of Health, British Columbia
PO BOX 9050
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Victoria, BC V8W9E2
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Honourable Minister,

On behalf of the Network of Rare Blood Disorder Organizations (NRBDO), I am writing today with serious concerns regarding your government's position on compensated plasma donation.

The NRBDO is Canada's unified patient voice on matters of blood supply and safety. We represent those Canadians who use these products in question - whose lives depend on plasma-based products, such as those living with Primary Immunodeficiency, Thrombotic Thrombocytopenic Purpura, and Hemophilia.

We find it concerning when health officials confuse and alarm the public by connecting paid plasma collection to voluntary blood collection. The NRBDO agrees that donation of fresh blood components, collected by a not-for-profit blood establishment such as Canadian Blood Services (CBS) must remain voluntary and non-compensated.

However ***plasma products*** are manufactured by for-profit multi-national corporations, and sold to the provinces and territories, just like any other drug. The manufacture and sale of plasma products is almost entirely a private, for-profit operation, with plasma being the main raw ingredient. To say that the compensated collection of this ingredient puts our public health care system in peril is a stretch at best, and fear-mongering at worst.

With no evidence of safety risks, and no evidence of threats to the voluntary collection of blood, paid plasma can help with the global supply shortage, ensuring patients can access plasma products when they need them.

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The NRBDO is committed to ensuring the patient voice is heard, and working with governments, CBS and H-Q to protect the safety and availability of blood products in Canada. We urge you not to prohibit this practice in British Columbia.

Sincerely,

Whitney Goulstone
Chair, NRBDO

Answering T.T.P.
Thrombotic Thrombocytopenic Purpura

Aplastic Anemia & Myelodysplasia Association of Canada

Canadian Association for Porphyria
Association Canadienne de Porphyrie

Canadian Hemophilia Society
Help Stop the Bleeding

IPO
Canadian Immunodeficiencies Patient Organization

CORD Canadian Organization for Rare Disorders

FA Fanconi Canada

HAE AOH Canada

Sickle Cell Disease Association of Canada / Association d'anémie falciforme du Canada
SCDAC AAFC

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.