



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

September 22, 2020

MLA Tany Yao
Alberta Legislative Assembly
Tany.Yao@assembly.ab.ca

Re: Bill 204, the Voluntary Blood Donations Repeal Act

Mr. Yao,

We, the Network of Rare Blood Disorder Organizations (NRBDO), are writing today in support of your private members bill, Bill 204, to repeal the Voluntary Blood Donations Act. Patient needs require that Canada leave open the option for the compensated collection of plasma, and Alberta's 2017 Voluntary Blood Donations Act prevents that.

The NRBDO is a pan Canadian coalition of not-for-profit organizations representing people with rare blood disorders and/or people with chronic conditions who are recipients of blood or blood products or their alternatives. Together, we represent many thousands of patients. As such we have had a vested interest in blood safety and supply in Canada and internationally since forming in 2004.

Plasma-derived medicinal products (PDMP) such as immune globulin are manufactured by for-profit multi-national corporations to treat a number of medical conditions and rare diseases, and sold to the provinces and territories, just like any other drug. The manufacture and sale of PDMPs is almost entirely a private, for-profit operation, with plasma being the main ingredient.

Plasma collected from volunteer Canadian donors represents a mere 14% of the current need in this country for immune globulin, a need that is growing by about 6-10 per cent annually.¹ Canada relies on the U.S.A. to supply the remaining 86% of our plasma needs, where donors receive money for donating their plasma.

There is a very real concern in the global market that demand will soon exceed supply. Advocates have been warning that should the United States ever decide not to sell plasma to Canada, or as countries not currently using PDMPs decide to open their doors to this medical advancement, Canada's heavy reliance on international plasma will put us in a very weak position to negotiate for better prices on our PDMPs, products Canadian Blood Service and Héma-Québec currently procure through a competitive tendering process. Indeed, rather than negotiating for lower prices, we may be put in a position of needing to negotiate to secure any PDMPs at all for Canadian patients.

¹ Health Canada. (2018) *Protecting Access to Immune Globulins for Canadians: Final Report of the Expert Panel on Immune Globulin Product Supply and Related Impacts in Canada*. Ottawa, ON: Her Majesty the Queen in Right of Canada, as represented by the Minister of Health.

Increasing our plasma sufficiency is crucial, and as a Health Canada Round Table discussion on compensating plasma donors found: “No country in the world has been able to meet their need for plasma with a solely volunteer model.”

Because of COVID-19, plasma donations are down globally and we can expect IG shortages unless plasma donations increase. It is vital that Canadians contribute to the global supply of plasma.

It is the position of the NRBDO that since there is no evidence of safety risks, and no evidence of threats to the voluntary collection of blood, compensated collection of plasma can help with the global plasma supply, ensuring patients can access plasma products when they need them.

The position on this issue held by the NRBDO and its constituent groups whose members rely on PDMPs for their very survival is based on the latest medical research and is shared by similar patient organizations around the world. It is also validated in the final report of the Expert Panel on Immune Globulin Product Supply and Related Impacts in Canada, *Protecting Access to Immune Globulins for Canadians*.

The NRBDO is committed to ensuring the patient voice is heard, and working with governments to protect the safety and availability of blood products in Canada. We thank you for bringing this issue forward in your private members bill, and urge all Alberta MLAs to support Bill 204.

Thank you,



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

cc: Hon. Tyler Shandro, Minister of Health
MLA David Shepherd, NDP Health Critic