



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

June 25, 2018

Senate of Canada
Ottawa, ON
K1A 0A4

Re: Bill S-252, Voluntary Blood Donations Act (An Act to amend the Blood Regulations)

Honourable Senators,

We, the Network of Rare Blood Disorder Organizations (NRBDO), feel compelled to respond to Senator Wallin's new Bill S-252, the Voluntary Blood Donations Act, to offer the perspective of Canadians who rely on plasma-derived medicinal products (PDMPs) to stay alive.

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.

As Senator Wallin is well aware, plasma collected from volunteer Canadian donors represents a mere 17% of the current need in this country for immune globulins, a need that is growing by about 6-10 per cent annually.¹ Canada relies on the U.S. to supply the remaining 83% of our plasma needs, which come from American paid donors.

In fact, the U.S blood system is able to meet their needs for whole blood donations for the supply of fresh blood components through a robust voluntary, not-for-profit donation system, similar to Canada's, while simultaneously supplying 70% of the world's plasma supply through a paid collection system. It would appear that the two systems are able to function side by side.

In 2016, referencing other countries that use paid models, such as the United States, Germany, the Czech Republic and Austria, Canadian Blood Services CEO Dr. Graham Sher stated, "In those places, one has not seen the emergence of for-profit plasma industry have a negative impact on blood collection."²

Since the tainted blood tragedy of the 1970s and 1980s, huge changes have taken place in the regulation and manufacture of PDMPs. Thanks to rigorous donor screening, testing of donations and viral clearance procedures, these products have maintained a perfect safety record with regard to pathogen transmission for the last 25 years. It is false to state that PDMPs from compensated donors are less safe than those from unpaid donors.

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.

² Wong, Julia. "Pay for Plasma: The economics behind paid and unpaid systems." Global News.
<https://globalnews.ca/news/2652186/pay-for-plasma-the-economics-behind-paid-and-unpaid-systems>

Therefore, it is the position of the NRBDO that with 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 supply, ensuring patients can access plasma products when they need them. This position is validated in the recent 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 agrees that donation of whole blood and other fresh components such as platelets, collected by not-for-profit blood establishments such as Canadian Blood Services (CBS) and Héma-Québec, must remain voluntary and non-compensated.

However, plasma-derived 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, or, as Senator Wallin has suggested, could lead to an issue of National Security, is a stretch at best, and could be interpreted as fear-mongering.

If Senators believe that this is an ethical issue, then the proposed Bill should not only prohibit payment for plasma donation to Canadians; to be logical and consistent, it should also prohibit the import of all plasma products manufactured from paid donations. The result would be hundreds of Canadians dying and thousands becoming sick and unable to work. Hardly ethical.

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.”³ Therefore, the NRBDO agrees with the findings of Kretschmer et al who concluded, “All measures improving the supply of safe blood, including monetary compensation, should be objectively discussed without prejudice.”⁴

While it is correct to state that the NRBDO and some of its member organizations receive grants from a number of pharmaceutical companies (only a few of which collect and fractionate plasma, and none of which collect plasma in Canada), it is entirely false to suggest that our common position on the issue of payment for plasma donation is in any way influenced by financial considerations. Some of our member organizations were decimated by Canada’s tainted blood tragedy and the pain is still very real. Our goal is the optimal supply of safe, high-quality blood and plasma-derived medicinal products for patients. To claim anything different, without the least evidence, is frankly insulting. Moreover, the positions on this issue held by NRBDO and its constituent groups whose members rely on plasma-derived medicinal products for their very survival are based on the latest medical research and are shared by similar patient organizations around the world.

³ Health Canada. *Round Table Discussion on Payment of Plasma Donors in Canada – Summary Report*. April 10, 2013. <https://www.canada.ca/en/health-canada/services/drugs-health-products/public-involvement-consultations/biologics-radiopharmaceuticals-genetic-therapies/round-table-discussion-payment-plasma-donors-canada-summary-report.html>

⁴ Kretschmer V, Weippert-Kretschmer M, Slonka J, Karger R, Zeiler T. *Perspectives of paid whole and plasma donation*. *Developmental Biology* 2005;120:101-11.

The NRBDO is committed to ensuring the patient voice is heard, and working with governments, CBS and Héma-Québec to protect the safety and availability of blood products in Canada. We urge Senators to oppose Bill S-252, and we would be more than willing to appear before a Senate committee to present our views on this issue and answer questions.

Thank you.

Sincerely,



Gergana Sandeva
Chair, Network of Rare Blood Disorder Organizations (NRBDO)