



**Expert Panel on Immune Globulin Product Supply and Related Impacts in Canada
REQUEST FOR INPUT: PATIENT / PRODUCT USER GROUPS**

Name of organization: Network of Rare Blood Disorder Organizations (NRBDO) / Réseau des Associations Vouées aux Troubles Sanguins Rares (RAVTSR)

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The NRBDO is a pan Canadian coalition of not-for-profit organizations representing people with rare blood disorders and/or people with a chronic condition who are recipients of blood or blood products or their alternatives.

Member groups:

- Answering TTP (Thrombotic Thrombocytopenic Purpura)*
- Canadian Association for Porphyria (CAP)
- Canadian Hemophilia Society (CHS)*
- Canadian Immunodeficiencies Patient Organization (CIPO)*
- Canadian Organization for Rare Disorders (CORD)
- Fanconi Canada
- HAE Canada (Hereditary Angioedema)*
- Sickle Cell Disease Association of Canada (SCDAC)
- Thalassemia Foundation of Canada (TCF)

*These member groups represent patients who rely on plasma-derived products. The individual submissions of these patient groups will provide the patient demographic information you are seeking.

The NRBDO has had a vested interest in the blood safety and supply in Canada for over a decade, from the perspective of patients who rely on these products to stay alive.

Products Used To Treat Conditions Represented By NRBDO Member Organizations

<u>Disease</u>	<u>Treatment Product</u>	<u>Plasma Source</u>
TTP (Thrombotic Thrombocytopenic Purpura)	Untreated Plasma	Unpaid donors
	Solvent detergent treated plasma	Paid donors in U.S.
Immunodeficiency	Immunoglobulin products	Paid donors in U.S.
Hereditary angioedema	C1 esterase inhibitor	Paid donors in U.S.
A1 antitrypsin deficiency	A1 antitrypsin concentrate	Paid donors in U.S.
Clotting factor deficiencies		
Factor II, VII, X, XI, and XIII deficiencies	Plasma derived products	Paid donors in U.S.
Factor I deficiency	Plasma derived product	Unpaid donors
Factor V deficiency	Solvent detergent treated plasma	Paid donors in U.S.
von Willebrand disease	Humate	Unpaid donors
	Wilate	Paid donors in U.S.

Position related to the mandate of this panel:

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, paid plasma can help with the global supply shortage, ensuring patients can access plasma products when they need them.

The donation of whole blood, 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. Indeed, these products are supplied at no direct cost to patients by CBS and Héma Québec, which could be a model for the rest of our public health system.

Additional information or evidence related to the mandate of the Panel:

At the present time, thousands of Canadians with chronic hematologic and immune-system disorders rely on plasma-derived products to maintain their health and keep them alive; and most of the plasma used to manufacture of these products comes from paid donors in the United States.

Of the 30 plasma-derived products distributed by the Canadian Blood Services (CBS), only two are produced wholly from unpaid Canadian donors. Twenty-six are produced solely from plasma from paid donors in the U.S., and two (immune globulin and albumin) are produced from a combination of both sources. More than 80 percent of the plasma required for these two products is produced from compensated U.S. donors. We submit that paying Canadians is no more or less ethical than paying Americans, as we do today for most of the plasma-derived medicinal products used across Canada.

It is of note to our group that Canadian Blood Services (CBS) is not without some bias on this issue, and has changed its position on the impact of paid plasma collection on voluntary whole-blood donation:

- In 2012 CBS closed a plasma collection facility citing the declining demand for plasma for transfusion.¹
- In 2016, referencing other countries that use paid models, such as the United States, Germany, the Czech Republic and Austria, CEO Dr. Graham Sher told Global News that “In those places, one has not seen the emergence of for-profit plasma industry have a negative impact on blood collection.”²

¹ “Canadian Blood Services announces closure of Thunder Bay Plasma Centre.” March 29, 2012.

<https://blood.ca/en/journalists/canadian-blood-services-announces-closure-thunder-bay-plasma-centre>

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>

- Now in 2017, with a decrease in demand for whole blood,³ and an increase in demand for plasma-derived products,⁴ CBS finds plasma to be an integral part of its business plan moving forward, and as their interests in plasma have changed, so has its position on the dangers of compensated plasma collection. The proposed business plan includes provinces and territories providing \$855 million in additional funding over the next seven years to open 40 plasma collection centres in an attempt to raise Canada's self-sufficiency from 17% to 50%.⁵

While we have searched for this newly mentioned evidence about negative impacts of paid plasma collection on the voluntary whole-blood donation system, we have found none. What we have found however is that the USA is able to meet their needs for whole blood through a robust voluntary, not-for-profit donation system 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.

As a Health Canada Round Table discussion on compensating plasma donors concluded: "No country in the world has been able to meet their need for plasma with a solely volunteer model."⁶

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."⁷

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 thank you for the opportunity to submit input to the panel.

³ Wald, Matthew. "Blood Industry Shrinks as Transfusions Decline." New York Times.

<https://www.nytimes.com/2014/08/23/business/blood-industry-hurt-by-surplus.html?mcubz=0>

⁴ "Sales of Plasma Protein Therapeutics to Rise in Response to Increasing Demand for Immunoglobulin, says TMR." July 19, 2016. <http://www.prnewswire.com/news-releases/sales-of-plasma-protein-therapeutics-to-rise-in-response-to-increasing-demand-for-immunoglobulin-says-tmr-587444041.html>

⁵ Grant, Kelly. "Blood agency seeking \$855-million in funding to boost plasma supply, document reveals." The Globe and Mail. <https://beta.theglobeandmail.com/news/national/blood-agency-seeking-855-million-in-funding-to-boost-plasma-supply-document-reveals/article35980339/?ref=http://www.theglobeandmail.com&>

⁶ "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>

⁷Kretschmer V, Weippert-Kretschmer M, Slonka J, Karger R, Zeiler T. Perspectives of paid whole and plasma donation. *Developmental Biology* 2005;120:101-11. <https://www.ncbi.nlm.nih.gov/pubmed/16050162>