

Network of Rare Blood Disorder Organizations (NRBDO)

Testimony Regarding Bill 21

Spokesman: Tom Alloway

Testimony from the Network of Rare Blood Disorder Organizations

The Network of Rare Blood Disorder Organizations (NRBDO) is a coalition of organizations that represent patients who are living with several different blood disorders. (A list of the member organizations is appended.) These organizations seek to develop and advocate for best practices in health care delivery for people with blood disorders, many of which require treatment with blood, blood products or their alternatives. The member organizations believe that their voices can be more effectively heard if they coordinate their work and advocacy to secure and maintain patient access to the kind of medical care that empowers patients to live lives that are as nearly normal as possible.

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. (A list of the plasma-derived medicinal products used by people represented by NRBDO member organizations is attached.) Of the 30 plasma-derived products distributed by the Canadian Blood Services (CBS), only one is produced wholly from unpaid donors. Twenty-seven 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. Seventy percent of the plasma required for these two products is produced from compensated U.S. donors. We submit that paying Ontarians is no more or less ethical than paying Americans, as we do today for most of the plasma-derived medicinal products used in Ontario and across Canada.

The members of the NRBDO have paid close attention to blood safety and supply issues over the last decade. In 2010 and 2011, the NRBDO endorsed the Dublin Consensus Statements (attached) which recognized the use of payment for blood and plasma donation and acknowledged valid roles for both paid and unpaid donation systems in maintaining a safe and adequate supply of both fresh blood components and plasma-derived medicinal products for patients worldwide. In 2014, the member organizations of the NRBDO endorsed a background document and a policy developed by the Canadian Hemophilia Society (attached) that similarly acknowledge the role of both paid and unpaid donation systems for producing an adequate supply of plasma for the manufacture of medicinal products. The NRBDO, therefore, believes that Bill 21, by forbidding payment for plasma donation, fails to promote the best interests of patients who need plasma-derived medicinal products.

Decisions on licensing individual plasma collection centres are the responsibility of Health Canada, based on the strictest industry and regulatory standards. While the collection and provision of fresh blood components is a national issue; the collection, manufacture and provision of plasma-derived medicinal products is a global issue; decisions on such an issue must be made based on up-to-date safety and supply data, not misconceptions that date from the 1970s and 1980s.

Those who oppose paying donors do so on the basis of two main arguments:

1. Blood from paid donors was an important source of products contaminated with HIV and other viruses that led to the tainted blood crisis of the 1980's.
2. Payment for blood donation might endanger the viability of our current system of unpaid donation.

With respect to the first argument, we note a number of important changes that have occurred. Chief among these are the development of sensitive tests that are capable of detecting contamination with viruses that are known to endanger the health of blood-product recipients and procedures such as solvent-detergent treatment and filtration that kill or remove viruses during the manufacture of plasma-derived medicinal products. In addition, manufacturers of plasma-derived products have developed a host of other safety measures through voluntary industry standards that surpass Health Canada and FDA regulations. These include a quarantine of first-time plasma donations until both the first donation and a second donation have proven negative for all pathogens, an inventory hold on plasma to allow for post-donation information to be known, and NAT testing for five viruses—HIV, HBV, HCV, hepatitis A and parvovirus B19—not only on individual donations but also on pools of plasma.

With respect to the second argument, we note that implementation of a paid-donor system in the United States and other countries has not prevented the maintenance of unpaid donor systems. There is no evidence from countries where paid and unpaid systems coexist that payment for plasma has jeopardized the unpaid collection system, although this would need to be closely monitored if paid plasma centres were to open in Canada.

For the reasons outlined above, the NRBDO opposes Bill 21 and hopes that the Ontario Provincial Parliament will defeat it.

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 Sovent detergent treated plasma | Unpaid donors 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 I, II, VII, X, XI, and XIII deficiencies | Plasma derived products | Paid donors in U.S. |
| Factor V deficiency | Sovent detergent treated plasma | Paid donors in U.S. |
| von Willebrand disease | Humate Wilate | Unpaid donors Paid donors in U.S. |

Members of the Network of Rare Blood Disorder Organizations

Answering TTP (Thrombotic Thrombocytopenic Purpura)

C/O Sydney Kodatsky, Executive Director

22 Prince George Drive

Toronto, Ontario M9A 1Y1

Tel.: (416) 792-4656

Web site: www.AnsweringTTP.org

E-mail: answeringttp@gmail.com

Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC)

11181 Yonge Street, Suite 321

Richmond Hill, Ontario L4S 1L2

Tel.: 905-780-0698

Tel.: 1-888-840-0039

Fax: 905 780-1648

Web site: www.aamac.ca

E-mail: info@aamac.ca

Canadian Association for Porphyria

13604 108 Ave Edmonton, AB T5M 2C8

Email: canadianassocforporphyria.acp@gmail.com

Canadian Hemophilia Society (CHS)

666 Sherbrooke ouest, Suite 301

Montreal, Quebec H3A 1E7

Tel.: 514-848-0503

Tel.: 1-800-668-2686

Fax: 514-848-9661

Web site: www.hemophilia.ca

E-mail: chs@hemophilia.ca

Canadian Immunodeficiencies Patient Organization (CIPO)

8516 - 18 Avenue SW

Edmonton, Alberta T6X 0R7

Web site: www.cipo.ca

E-mail: info@cipo.ca

Canadian Organization for Rare Disorders (CORD)

151 Bloor Street West, Suite 600

Toronto, Ontario M5S 1S4

Tel : 416-969-7464

Tel.: 1-877-302-7273

Fax: 416 969-7420

Web site: www.raredisorders.ca

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Fanconi Canada

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HAE Canada (Hereditary Angioedema)

1081 Carling Avenue, Suite 408

Ottawa (ON) K1Y 4G2

Tel: 613-761-8008

Fax: 613-761-5927

Web site: www.haecanada.org

Executive Director: Tim Howe

Email: thowe@haecanada.org

Sickle Cell Disease Association of Canada (SCDAC)

1030 Mountcastle Crescent

Pickering, Ontario L1V 5H9

Tel.: 905.420.0666

Fax: 905.831.7939

Web site: www.sicklecelldisease.ca

E-mail: info@sicklecelldisease.ca

Thalassemia Foundation of Canada (TCF)

338 Falstaff Avenue, suite 204

North York, ON M6L 3E7

Tel. 416-242-THAL (8425)

Fax: 416-242-8425

Web site: www.thalassemia.ca

E-mail: info@thalassemia.ca