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Alpha-1 Antitrypsin  
Deficiency Canada Inc.  
(Alpha-1 Canada)

Providing information and support for Alpha-1 Antitrypsin Deficiency

Soutenir, informer et éduquer les personnes atteintes d'un déficit en alpha-1-antitrypsine

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April 9, 2014

Hon. Deborah Matthews, MPP (London North Centre)  
Minister of Health and Long-Term Care  
Ministry of Health and Long-Term Care  
10th Floor, Hepburn Block,  
80 Grosvenor Street,  
Toronto, Ontario M7A 2C4

Dear Minister,

We are writing to you on behalf of the Board of Directors of Alpha-1 Canada and hundreds of Ontarians with respect to Bill 178, the Voluntary Blood Donations Act, 2014. These are the very people your bill purports to protect but in fact, both short term and long term, will significantly cause harm.

As the representative organization for a population of Canadian patients who use a plasma-derived treatment on a weekly basis we are uniquely positioned to address the issue of paid plasma donations, especially those used to manufacture plasma fractionated products. The people we represent have a right to be consulted and listened to on this issue before any such bill is written or passed.

Alpha-1 Canada is dedicated to providing information, education and support to Canadians affected by the rare genetic disease known as Alpha-1 Antitrypsin Deficiency (Alpha-1) and also dedicated to providing information and education to the Canadian medical community about Alpha-1.

Bill 178 seems to have been drafted in a vacuum with little research and no consultation with those who will be affected. As a result there are many unintended consequences which will affect many patients, including those we represent, in not only negative but life-threatening ways.

We are calling on you to stop this process immediately and begin anew with a more thoughtful, consultative process that takes into account all of the issues surrounding plasma donations and the many Ontarians it negatively affects.

Research has indicated that there is no significant difference in the safety of compensated or non-compensated sources for plasma; the issue is more accurately about whether we should pay Canadians for plasma donations. Presently, Canadian patients requiring plasma and plasma-derived products depend upon plasma or plasma-derived products purchased from the United States and Europe where paid donations make up the overwhelming majority of the supply. Eighty per cent of the Canadian and world supplies of plasma derived-products are manufactured in countries other than Canada from the plasma of paid donors.

Many plasma-derived products are used in the treatment of rare disorders including alpha-1 antitrypsin deficiency and are already manufactured in the United States and Europe from American and European source plasma from paid donors.

By way of example,

- Alpha-1 Proteinase Inhibitor is used to treat Alpha-1 Antitrypsin Deficiency a genetic deficiency which may result in life-threatening lung disease in adults and/or liver disease in people of any age.
- Coagulation factors, essential for blood clotting, are used to treat genetic bleeding disorders and surgical bleeding including Hemophilia A and B and Von Willebrand disease.
- Immunoglobulins are proteins used to neutralize foreign objects such as bacteria and viruses and are used to treat primary immunodeficiencies, secondary immunodeficiencies and Chronic Idiopathic Demyelinating Polyneuropathy (CIDP) - a rare disorder of the peripheral nerves.
- Hyperimmune Globulins are used to treat rabies, tetanus, hepatitis, Rh negative pregnancy and in liver transplant and surgeries.
- Albumin, a protein important in regulating blood volume is used in emergency and surgical medicine to treat shock, severe burns and during surgeries.
- These are the ones that we know of, there could well be others.

None of these products are manufactured in Canada, but rather in the United States and Europe from paid plasma donations.

Canadian Blood Services and Héma-Québec are increasingly dependent on source plasma from the United States from paid donors for the supply of plasma-derived products and given current plans, they will be unlikely to provide for more than 30% of the required immunoglobulin supply alone needed to meet the needs of Canadian patients through voluntary donations.

Canadian governments have a right and responsibility to regulate the donation process. Canada currently purchases 80% of its plasma and plasma-derived products from suppliers outside of the country. Purchasing product from outside the country seriously limits Canadian governments' ability to regulate the donation process. The banning of paid donations within our country will increase our dependence on outside sources and other governments' regulation of the process.

There is a worldwide shortage of plasma-derived products. Canada should contribute its fair share to ensure that there is an adequate supply of plasma and plasma-derived products worldwide. This goal can only be reasonably met if we develop a responsibly regulated paid plasma contribution system in addition to the system of donated plasma collection.

The facts which the drafters of Bill 178 seem to have ignored are legion.

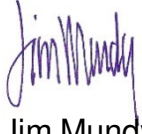
- For example, plasma collection sites in Canada where donors are paid have operated under Health Canada and United States FDA regulation and oversight for many years with no safety concerns in the last 20 years.
- Plasma-derived products are life-saving therapies for a number of rare diseases that affect thousands of Canadians.
- Effective donor selection and testing technologies are applied to both paid and non-paid donations in Canada, the United States and Europe.
- Highly effective viral elimination/reduction steps are applied to plasma-derived products.
- Plasma-derived products from paid donors have not been shown to transmit HIV, HBV or HCV in more than 20 years.

It is somewhat hypocritical to suggest that Canadians should not be paid for the time and effort involved in donating plasma because there is currently a readily available supply from other countries from donors who are paid. With the many global catastrophes constantly occurring this supply could drastically diminish in a heartbeat.

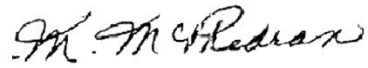
Once again we implore you to stop Bill 178, take a step back, investigate and give this issue the obligatory attention it deserves. Rushing this bill through the Legislature without proper consultation will have disastrous effects on vulnerable patients.

We await a timely reply and look forward to a necessary consultative, investigative process where we and all well deserving Ontarians can be heard.

Sincerely,

Handwritten signature of Jim Mundy in blue ink.

Jim Mundy  
Executive Director  
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Handwritten signature of Mimi McPhedran in black ink.

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