

11 April 2014

**Hon. Deb Matthews**

Deputy Premier of Ontario  
Minister of Health and Long Term Care  
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Dear Minister Matthews,

On behalf of the Canadian Organization of Rare Disorders (CORD), our patient groups, and the 2.8 million Canadians affected by rare disorders, I am writing to express our strongest objection to the Ontario government's Bill 178: An Act to ensure that blood and blood components are donated freely. This bill is reprehensible on so many levels.

For the past two decades, Canadians have relied on paid donors in the USA for about 80 to 90% of our plasma products. We are not unique in that respect. What is frightening about Bill 178 is that it will ensure that Canadians (or at least Ontarians) will always have to rely on paid plasma donors in other jurisdictions. No country in the world is able to meet its needs for plasma products without a paid plasma program. We only need to look back in Canada's history of failed plasma collection centres in Ontario and PEI to reaffirm the fact that even with huge investments in advertising and recruitment, we are unable to build a sufficient unremunerated plasma donor base.

Even worse, Bill 178 threatens to destabilize Canada's blood system and undermining public trust. For example, a patient scheduled for surgery denied permission to use albumin (a life-saving blood replacement product) during surgery. "How safe is this product? I learned it's made from plasma from paid donors, and the Health Minister has introduced a law to ban paid donors in Ontario."

A patient with a rare disorder whose life depends on regular infusions of plasma-derived products recalled in years past when concerns over "paid donations" dominated the media and no one wanted to donate. "Thank God we have had a stable supply for the past decade, 90% of which comes from paid donors in the USA. But what if the American government follows Ontario's lead and bans paid donors, or simply refuses to provide plasma products to Canadian patients? We would all be dead."

What makes the bill even more reprehensible is the fact that it is contrary to all of the best evidence about paid plasma donations.

- There is NO evidence of any safety risks with paid donor plasma products for the past two decades.
- There IS good evidence that the screening of paid plasma donors is more rigorous than the screening of "unpaid" whole blood donors.
- There is NO evidence that paying plasma donors cannibalizes donors from the "unpaid" whole blood donor program.

- There is evidence that countries with paid plasma programs (Germany, Austria, USA) also have higher rates of public participation in unpaid whole blood donor programs.
- There is NO evidence that any country has managed to achieve self-sufficiency in plasma products relying entirely on unpaid plasma donors.
- There IS evidence that unpaid plasma collection centres, even with huge investments in advertising and recruitment, cannot attract sufficient donors to justify operation.

Every reasonable voice, including those of patient groups, clinicians, and blood system experts, has supported the necessity of paid plasma donors. As the volunteer president of the Canadian Hemophilia Society during the 1990's, I contributed hundreds of hours attending the inquiry into tainted blood hoping to understand how so many Canadians could have been infected. While the paid donor system was a contributing factor, there were as many people infected by unpaid blood donations. The real problems were screening, testing, and oversight. I donated hundreds more hours to what we felt was the real solution to avoiding a repeat of the past tragedy and that was a new blood system where decisions would be evidence-based, transparent, accountable, and inclusive of the users.

Whole blood donors typically donate only 1 or 2 times a year, but in order for a plasma collection program to be cost-effective, donors must be willing to contribute on a regular basis, often several times a month. Past experience has demonstrated that advertising would cost more than the \$20 honorarium per donation; moreover, no amount of advertising will induce a donor to come in regularly without compensation for his/her time. Frankly, I would much rather pay a donor than an advertising company.

The facts are unambiguous. Paid donors living in the USA contribute up to 90% of the plasma products needed by Canadian patients for emergency and chronic conditions. There have been no safety issues with paid plasma products. The costs of recruiting unremunerated donors are greater than the costs of honoraria, and Canada has been unsuccessful in all past attempts to collect sufficient plasma from unpaid donors. Demand for plasma products is increasing with newly identified uses in treatment and growing demand in middle and low-income countries. The consequence of Ontario Bill 178 will be to eliminate any possibility of Ontario donors helping to alleviate the worldwide need for plasma products and moving Canada toward self-sufficiency.

I learned much from Justice Krever throughout the Blood Inquiry and it is a disservice to his legacy to misuse his recommendations for political purposes. Based on past events, his call for unpaid blood and plasma donors was reasonable but he could have not anticipated today's environment with increased need for plasma-derived products and increased safety measures that equalize paid and unpaid donations. It is also disrespectful to those who were harmed under the previous blood system to ignore today's responsibility to assure a safe and adequate blood and plasma supply.

With Bill 178, the Ontario government threatens to undermine a decade and half of rebuilding public trust not just in the blood system but also in other issues. If we can't trust the Ontario government to act on the best evidence in this situation, how can we trust them



Canadian Organization  
for Rare Disorders

on other matters? On behalf of all patients reliant on plasma products and a trustworthy healthcare system, we urge the Ontario government not only to abandon this potentially destructive bill but also to put genuine resources and support into establishing a safe and cost-effective plasma donation program that includes paid donors.

Sincerely,

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