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[haecanada.org](http://haecanada.org)

July 12, 2013

Catherine Parker  
Senior Executive Director  
Director General's Office  
Biologics and Genetic Therapies Directorate  
Tunney's Pasture, Ottawa

Sent via email to: [BGTD.OPIC@hc-sc.gc.ca](mailto:BGTD.OPIC@hc-sc.gc.ca)

Re: HAE Canada Statement on Paid Plasma Donations

Dear Ms. Parker,

As President of HAE Canada (HAEC), the national patient organization representing people suffering from hereditary angioedema<sup>1</sup>, I appreciated participating in the April 10, 2013 round table discussion on the issue of paid plasma donations. We are responding to your invitation to Canadians to comment on the issue.

HAE Canada continues to share the stated positions of the Canadian Blood Services and the Canadian Hemophilia Society that support the long-held practice of using plasma products sourced from paid blood donors in treatment of rare blood disorders. Our official statement, which was shared with Health Canada on March 20, 2013, follows this letter. At the same time, HAEC is committed to supporting the safety of our plasma supply and we want to ensure that strict adherence to annual inspections of plasma donation centres be maintained and that reports be made available to stakeholders in a timely fashion.

If we can be of any assistance by providing further information on behalf of our patients and/or the health care professionals who support our patients, please contact me. I can be reached directly at [tamara.armoogan@haecanada.org](mailto:tamara.armoogan@haecanada.org).

Sincerely,

A handwritten signature in cursive script, appearing to read 'Tammy Armoogan'.

Tammy Armoogan, RN  
President

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<sup>1</sup> Hereditary Angioedema, or HAE, is a rare, debilitating, and potentially life threatening genetic blood disorder that affects about 1 in 50,000 Canadians.

**cc:**

**HAEC Board of Directors**

Tammy Armoogan, RN, HAE patient and parent

Jacquie Badiou, RN, HAE patient and parent

Stephen Betschel, MD

Caroline Farmer, RN

Martine Paquette, HAE patient and parent

Anne Rowe, RN, BScN, MEd, HAE patient

Scottie Sanford, HAE patient and parent

Paulette Vinette, CAE, FASAE, Executive Director

**HAEC Mission Statement**

To partner with patients, health care professionals, the scientific community, government policy makers and industry to ensure all hereditary angioedema patients have access to timely and appropriate treatment based on an individual and comprehensive plan to ensure they lead a full and healthy life.

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## HAE Canada on Paid Blood Plasma Donations

Toronto, March 20, 2013

HAE Canada shares the stated positions of the Canadian Blood Services<sup>1</sup> and the Canadian Hemophilia Society<sup>2</sup> that support the long-held practice of using plasma products that were sourced from paid blood donors in treatment of rare blood disorders.

It has been recognized that the demand for plasma products has exceeded the Canadian capacity of plasma collection for decades. In fact, most of the world's supply of fractionated plasma products comes from paid donors. 80% of the plasma needed to manufacture products used in Canada comes from the USA, where donors are very likely to be paid for their plasma donations. HAE Canada considers these products safe and essential.

Plasma derived products are life-saving therapies for a number of rare blood diseases that affect thousands of Canadians, including our members who live with hereditary angioedema (referred to as HAE). HAE is a rare blood disorder resulting from a deficiency in C1 esterase inhibitor. It is a chronic, potentially life-threatening illness that causes episodes of swelling commonly affecting the face, throat, abdomen, and extremities. If left untreated, an upper airway obstruction can prove fatal for HAE patients.

The majority of people with HAE have a defective gene that results in their body producing inadequate or non-functioning C1 Inhibitor – the blood protein that stops swelling. There is no cure for HAE yet. The efficacy of plasma-derived C1- Inhibitor as replacement therapy for acute attacks of HAE has been documented. Soon, new prophylactic therapies may also be available in most provinces. HAE Canada is a not-for-profit patient organization that provides education and support services for Canadian hereditary angioedema patients and their families.

For more information, contact HAE Canada at [info@haecanada.org](mailto:info@haecanada.org). Please visit the HAE Canada website<sup>3</sup> for further information about HAE and useful links.

Peter Waite, CAE  
Executive Director

1. [http://bloodservices.ca/CentreApps/Internet/UW\\_V502\\_MainEngine.nsf/9749ca80b75a038585256aa20060d703/6759ee5e17db02e385257b2d0065c052?OpenDocument](http://bloodservices.ca/CentreApps/Internet/UW_V502_MainEngine.nsf/9749ca80b75a038585256aa20060d703/6759ee5e17db02e385257b2d0065c052?OpenDocument)

2. <http://www.hemophilia.ca/files/Policy%20on%20Paid%20Plasma%20Donations%2029-05-2013.pdf>

3. <http://www.haecanada.org/understanding/useful-links/>