

HAE Canada Inc.
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April 14, 2025

Ms. Heather Jeffrey, President, Public Health Agency of Canada
Dr. Theresa Tam, Chief Public Health Officer of Canada
Public Health Agency of Canada
130 Colonnade Rd
Ottawa, ON, K1A 0K9
Sent via email

Dear Ms. Jeffrey and Dr. Tam:

My name is Michelle Cooper and I am writing to you on behalf of Hereditary Angioedema (HAE) Canada, a patient organization that represents and advocates for people with HAE and their caregivers.

HAE is a severely debilitating and life-threatening rare disease (1 in 10,000 to 1 in 50,000 people worldwide). It manifests as unpredictable, painful, recurrent/intermittent edema attacks in various parts of the body including the gastrointestinal tract, upper respiratory tract, larynx, extremities and face. Untreated attacks involving the larynx, nose or tongue are potentially life-threatening, as they can cause death by suffocation. It is critical that people with HAE have access to safe and effective treatments to not only improve their quality of life, but to potentially save their life.

Some available HAE treatments are derived from blood products, specifically C1-Esterase Inhibitor (Berinert), C1-Esterase Inhibitor Subcutaneous (HAEGARDA) and C1-Esterase Inhibitor [human] (Cinryze), making the safety of blood products extremely important for people with HAE. I am writing because we are concerned that the Public Health Agency of Canada (PHAC) has decided to end the Blood Safety Contribution Program as of April 1, 2026. HAE Canada aligns with Canadian Blood Services (CBS), Héma-Québec, and other stakeholders in viewing the discontinuation of the Blood Safety Contribution Plan as a significant setback to Canada's hemovigilance system.

During your meeting on February 13 with CBS and Héma-Québec, we understand that both operators expressed concerns about cancelling the Blood Safety Contribution Program. We also understand that CBS and Héma-Quebec offered to host a robust consensus conference to analyze the current gaps and recommendations for necessary improvements to national hemovigilance. Engagement in the forum is essential before making a final decision, as we have not found evidence showing that key stakeholders affected by the program's cancellation were consulted prior to the decision being made.

HAE Canada fully supports the proposed forum, and we are hopeful that PHAC accepts the invitation to attend and participate in this event. We look forward to hearing about your next steps.

Sincerely,

A handwritten signature in blue ink that reads "Michelle Cooper". The signature is fluid and cursive, with the first name "Michelle" being more prominent than the last name "Cooper".

Michelle Cooper
HAE Canada President