

From: nigel hamilton <nigelphamilton@yahoo.co.uk>

Sent: 28 May 2024 22:54

To: Donnelly, Roisin <Roisin.Donnelly@niassembly.gov.uk>

Subject: Re: Committee for Health consideration of the establishment of a UK-wide Infected Blood Compensation Scheme

Dear Roisin,

Can I ask that a copy of the Societies draft to the Cabinet Minister be attached to Health Committee members papers to further indicate the issue of concern we would have following the Inquiry Recommendations supporting Advocacy by the Core Haemophilia Organisations and the current financial and man hours pressure we are experiencing at an unprecedented rate.

It will follow by email

Kindest
Nigel
Chair HNI



The Rt Hon John Glen MP, Paymaster General

Sent by email to ministerial.correspondence@cabinetoffice.gov.uk

28 May 2024

Dear Mr. Glen

As you will be aware the UK charity sector is operating in a very challenging environment. According to the Value of Giving index charitable donations have fallen from £9.5bn pre pandemic and the Cost of Living crisis to £5bn, whilst demand for support has surged.

Since your announcement in the House of Commons on 21 May 2024 on compensation in response to the report's publication, the haemophilia patient organisations have been inundated with calls and emails from our community confused and concerned about the implications. As we are small organisations already struggling to raise income you can imagine the additional burden this has incurred, however we still have the responsibility to provide the support for everyone in the UK with a bleeding disorder and advocate for the patient voice.

Sir Brian Langstaff included in his recommendations in the within Infected Blood Inquiry final report the importance of giving patients this a voice. Further than that the patient voice should be enabled and empowered by charities who should receiving receive funding specifically for patient advocacy including the UK Haemophilia Society, Haemophilia Scotland and Haemophilia Northern Ireland.

The Haemophilia Society has invested over £600k from its reserves since 2018 in our work supporting the Infected Blood Inquiry and our members infected and affected. We are not immune to the challenges across the charity sector which has, according to Third Sector magazine, -seen more charities close in the last 6 months than in the last 6 years combined.

If our organisations are not to join that shocking statistic we need interim long term financial support immediately or at least initially an immediate interim contribution to continue to advocate for our community at this pivotal stage in the long campaign for truth and justice. We would welcome the opportunity to meet to discuss further.

Yours sincerely

C. Smith

Chair, the Haemophilia Society UK

Bill Wight

Chair, Haemophilia Scotland



Chair, Haemophilia Northern Ireland