



The Haemophilia Society  
52B Borough High Street  
London  
SE1 1XN

Sir Brian Langstaff  
Chair  
Infected Blood Inquiry  
5th Floor  
Aldwych House  
71-91 Aldwych  
London  
WC2B 4HN

29 November 2024

Dear Sir Brian

We write with increasing concern that both the spirit and the letter of the recommendations resulting from the Infected Blood Inquiry's long and thorough investigation are being ignored by government.

It is almost five months since the current government was elected to office and we are frustrated by the lack of engagement between the Paymaster General, Nick Thomas-Symonds MP, and the infected and affected community or their representatives.

It is our collective view that the government is in danger of failing this community completely if it continues to avoid contact with those whose duty it is to serve, support and represent. We and our members are becoming frustrated and angry at the government's misguided belief that it knows best, and we can see the results of this lack of engagement in flawed, ill-informed decision-making.

This week we learnt that a clarification of guidance on interim compensation eligibility documents by the Cabinet Office has resulted in further trauma and upset for bereaved families. Applicants who had received emails from the Infected Blood Interim Estate Payments Scheme telling them that their claim had been successful, and that interim compensation would be paid on 7 December then received follow up emails telling them this was no longer the case.

It appears to our members that the government has stealthily moved the goalposts, cruelly offering compensation with one hand, while taking it away with the other. A new, opaque layer of bureaucratic burden has been placed on applicants, with no explanation or apology from the Cabinet Office. To the government these are simply applicants, but to us, and everyone who knows this community, they are bereaved mothers, fathers, sisters, brothers and children who have experienced unimaginable loss. Many of the applicants are now in their 80s and 90s and their suffering, shamefully, continues.

This extraordinary intervention by the Cabinet Office has left us all questioning the motivation for such a move and when the next one will come. It has damaged trust in the compensation process and has caused huge anxiety and distress, not just among those directly affected but for those waiting to apply.

We also believe that the current arrangements regarding reimbursement for legal support for the interim payment (which is only available to obtain a Grant of Probate/Letter of Administration) is inadequate. We think that recognised legal representatives who have expert knowledge of the infected blood community through



their work on the inquiry should be allowed to assist with applications for interim payments especially where the applicants are elderly or personal representatives have died and there is an appropriate chain of representation. This week's unwelcome development reinforces the developing concern that without properly funded legal support, people will be abandoned to a compensation process which appears to be getting ever more complex and difficult to navigate. We hope to share more detailed proposals on this important topic shortly.

As Chair of the Infected Blood Inquiry, you placed those directly impacted by the scandal at the heart of your work and, rightly, made clear your expectation that government and other institutions would do the same in implementing your recommendations. You criticised the 'lack of openness, transparency and candour' in state institutions. Today we feel the government continues to display those characteristics which makes it difficult to have confidence that it has the community's best interests at heart.

While the Infected Blood Compensation Authority appears to be involving the community in its work, it is clear that it is the Cabinet Office which holds the power, the budget and the decision-making clout.

We have repeatedly asked the Cabinet Office to address and discuss deep concerns over some aspects of its compensation scheme as well as consult with the community about the next set of regulations which are expected to be laid in March 2025. We are still waiting for a substantive response and a meeting.

We know that you are continuing to follow the response of the government closely and may intervene on some important issues. We ask you to continue this scrutiny and to do what you can to hold the government to account and address some of the serious issues raised in this letter before trust in this compensation process collapses.

Yours sincerely

**GRO-C**

Conan McIlwrath  
Chair, The Haemophilia Society

**GRO-C**

Nigel Hamilton  
Chair, Haemophilia Northern Ireland

**GRO-C**

Rachel Halford  
Chief Executive Officer, The Hepatitis C Trust

**GRO-C**

Andrew Evans  
Chair, Tainted Blood

**GRO-C**

John Dearden  
Chair, Haemophilia Scotland

**GRO-C**

Adam Fleming  
Director, BTMK Solicitors Limited