



The Rt Hon Nick Thomas-Symonds MP
Paymaster General
Cabinet Office
70 Whitehall
London
SW1A 2AS

9 October 2024

Dear Mr Thomas-Symonds

Supporting members of the Haemophilia Society and their families through the traumatic process of compensation is a central part of our charity's work.

We continue to be inundated by emails and phone calls from those infected and affected by contaminated blood products. Many of these enquiries are complex and emotional. All are looking for clarity and direction, which is currently missing from the scheme.

While we welcome the compensation proposals in general, there remain some key areas of concern which we believe must be addressed if this scheme is to have the trust and support of our community. We ask you to meet us as a matter of urgency so that we can set out what needs to be done to make this work.

Some of the issues our members have asked us to raise are:

- Additional autonomy awards of £10,000 and £15,000 for unethical research and testing are far too low
- No recognition of those with chronic hepatitis C who underwent interferon treatment and the additional impact this had on lives
- Concern that hepatitis C payment bandings do not reflect the suffering caused
- Compensation for people treated with infected blood products who self-cleared hepatitis C is very low and does not account for the physical and psychological impact of their infection
- Bereaved parents and children will receive very low compensation payments if they are not the beneficiary of the estate of their bereaved family member
- No compensation is being paid to siblings for their loss and suffering if they were over 18
- Compensation for lack of earnings should consider future career progression that was prevented from occurring rather than simply existing careers that were cut short

The Haemophilia Society

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President: Baroness Meacher Registered charity no. 288260. Charity Registered in Scotland no. SC039732
A company registered in England and limited by guarantee. Registered Company No. 1763614



- The estates of people who died young are being penalised because compensation for care and financial loss ceases on their death, leading to far lower compensation lump sums
- There is no compensation for the loss, psychological impact and suffering caused by exposure to vCJD
- A cap on compensation through the 'supplementary route' has been set but there is no information on what this cap will be and how it will affect people's compensation for loss
- The need for a 'date of infection' is causing anxiety and confusion
- Concern that inheritance tax will be paid by 'second generation' recipients, a likely result of money from estates going to elderly parents
- The bulk of compensation is being paid to estates which means that in many cases the compensation could be entailed away from those most impacted by someone's infection and death
- Only estate representatives can make decisions on care awards to affected people which in many families would not be appropriate.

We would also remind you of the Infected Blood Inquiry's recommendation that charities who support those infected and affected by contaminated blood products, including the Haemophilia Society, should receive government funding to continue their vital advocacy work. At a time when the charitable sector is in great financial distress, government funding is essential in ensuring that we give our members get the support they need.

It is crucial that you engage directly with us and our members' concerns. We are pleased to have constructive, on-going dialogue with the Infected Blood Compensation Authority and expect to have the same with the Cabinet Office, given your pivotal role in shaping this scheme.

Please remember that this is a community which has been let down far too often. The current lack of communication and general uncertainty about key details is doing nothing to build the trust which is so desperately needed to make this compensation scheme work.

We await your response.

Yours sincerely

A handwritten signature in black ink, appearing to read "Kate Burt".

Kate Burt
Chief Executive

A handwritten signature in black ink, appearing to read "Conan McIlwrath".

Conan McIlwrath
Chair-elect

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