

23 May 2025

This submission is written in my capacity as an individual and not as a campaign lead.

As a mono infected Hepatitis C victim living with the co-morbidities of having a bleeding disorder and living with serious liver disease, and who was infected at a young age, I do not feel any of my personal lived experience has been adequately addressed by the Government's compensation model.

Since the government published their compensation criteria on 21st May 2024, including the subsequent changes they have made, it is clear to me that the Government are doing everything in their power to minimise their financial exposure which isn't fair, reasonable or adequate.

As requested by the Infected Blood Inquiry I will keep this submission succinct and focused on what I consider to be the key issues related to the timeliness and adequacy of the response on compensation.

Much is said about the "*timeliness*" of compensation however my main concern is about the "*adequacy*" of compensation when it comes. My view is that I would far rather wait longer and be compensated properly rather than be undercompensated quickly. I strongly feel that I should at least have the opportunity to choose between these two options as should others.

In the light of the findings of the Infected Blood Inquiry report, Punitive or Exemplary damages should be made available to the victims of this scandal. These types of damages denote fault and the Inquiry report have highlighted many faults which were particularly reckless and grossly negligent, particularly in the case of Hepatitis which has been known about for at least eighty years.

The Governments' actions of importing infected blood products from the United States, even after being warned multiple times not to do so, was clearly

negligent and caused devastating levels of harm within the Haemophilia community. The practice of collecting blood to manufacture blood products in the UK from risky sources such as prisons was also extremely negligent. There was a clear failure to recognise that other less risky clotting products were or should have been made available. None of this has been adequately recognised in compensation. Moreover, there are a whole raft of issues related specifically to the bleeding disorder community which have also not been adequately recognised in compensation (*a list of which I include at the bottom of this submission, many of which were recognised and highlighted during the Inquiry).

Also in the case of mild and moderate Haemophilia patients in particular, evidence to the Inquiry highlighted there was often a failure to recognise that treatment was often unnecessary for non-life threatening elective medical procedures. Regardless of this, Factor VIII concentrates which were known to be infected were administered to mild and moderate Haemophilia patients without the patients being advised of the risks and without being informed they had been infected, even where there was clear medical evidence of infection which was particularly egregious and negligent. As someone with mild Hemophilia myself I wasn't even told that I had been given Factor VIII concentrate until well over a decade later, throughout which time I was highly infectious and began developing liver damage which has now led to serious liver disease. Had I been informed earlier I could have taken precautions including making lifestyle changes that could have protected my liver from increased levels of damage. The government's failure to not include any specific compensation for this clear negligence wasn't in anyway fair, appropriate or adequate. This negligence needs to be recognised in its own right.

I have been on treatment with interferon and ribavirin 5 times since 1995 and each treatment has had a devastating effect on both my physical and psychological health. On my second round of treatment I was put on a double dose interferon drug trial without being informed, which was devastating in its own right as I became extremely ill very quickly and didn't know why until I found out by chance that I had been put on a drug trial. The damage caused by these treatments has, and continues to have, long-term consequences, none of which have been adequately recognised. How can someone in my position receive the same level of compensation as someone that has either achieved SVR naturally, or has only ever received the newer direct-acting anti-retrovirals

(DAAs), there is no comparison. Again, this has not been adequately recognised.

As a result of the huge amount of oral and written evidence provided to the Infected Blood Inquiry and new evidence uncovered by Inquiry itself which is so damning, I believe there needs to be a day of reckoning against officials responsible in government the medical profession and blood services involved in this scandal at the time. I don't feel there can ever be full closure until legal action is taken against the responsible organisations and individuals that are still alive. The sheer arrogance of some of those responsible that gave oral evidence to the Inquiry was shocking to witness and in itself proved there was no contrition or recognition on their part that they had done anything wrong. While I understand that legal action against organisations and individuals is outside the Infected Blood Inquiries remit, I would like to request this point is at least mentioned somewhere in Sir Brians Langstaff's further report/statement.

I am currently registered with EIBSS and under that scheme there are 3 categories of Hepatitis C which include Stage 1, Special Category Mechanism (SCM) and Stage 2 Cirrhosis. It is also relevant to note that both the mono SCM category and mono Stage 2 Cirrhosis category under EIBSS both receive the same level of ongoing support as the mono HIV category which recognises the serious consequences of these infections. It was therefore shocking to see such a high level of disparity between the SCM/Cirrhosis and HIV categories under the compensation scheme. It was unsatisfactory enough to have Hepatitis C divided into 3 stages under the IBSS schemes, however, we then saw the addition of a 4th Hepatitis C category under the compensation scheme, which I believe has been deliberately designed to undercompensate Hepatitis C victims. If the Cabinet office where to revert back to a 3 stage scheme for Hepatitis C victims this would have the advantage of including both the SCM category and the Cirrhotic category in the Core route without the additional 4th stage where people are literally at deaths door. This would also require parity of compensation levels for mono SCM, mono Chirrhosis and mono HIV.

***A list of issues related to the bleeding disorder community which have not been adequately recognised in compensation:**

Most infected Heamophiliacs received letters informing them they are on the at risk register for vCJD with all the worry and complications it includes in terms of any and all future medical treatment;

being given massively pooled blood products even though government were warned multiple times;

followed the advice of Haematologists that were often given incentives to use certain Factor VIII products that benefited the Haematologist on a personal level;

followed the advice of the Haemophilia Society back in the day that encouraged the use of infected Factor VIII products;

being given the earlier extremely aggressive Interferon and Ribavirin treatments with the added complications of bleeding;

suffering discrimination by association, meaning that even those that don't have HIV are considered to have HIV by the fact they are Haemophiliacs which has always been linked to Haemophilia itself, particularly for those that have lived through the 70s and 80s. This involves both direct and indirect discrimination;

multiple EHMs and co-morbidities which are directly and more seriously complicated by having a bleeding disorder;

being treated with Factor VIII in PUP studies, treated as cheaper than chimpanzees regardless of whether an individual was registered at a specific centre; All haemophiliacs were none-consensually injected with infected material;

failing in the licensing regime, in particular (but not only) by allowing the importation and distribution from 1973 of blood products (Factor 8 concentrates) made in the US or Austria which carried a high risk of causing hepatitis, and were understood to be less safe than current domestic treatments for bleeding disorders;

using imported high risk blood products;

failure to achieve self sufficiency in the UK;

increasing size of pools to manufacture factor 8 although it was well known this would markedly increase viral transmission risk;

failing to finance research of viral inactivation of factor concentrates;

failing to have careful and rigorous donor selection/screening collecting blood from prisons;

adopting an attitude of denial towards risks of factor concentrates;

treating with ever increasing volumes of concentrate despite the risk;

failing to respond to serious risks of infection by making treatment adjustments such as using Cryoprecipitate or DDAVP instead of Factor concentrates, and for example avoiding prophylactic treatment altogether;

treating children with multiple, riskier commercial concentrates prophylactically as objects for research rather than using safer treatments;

falsely reassuring the public victims that non A non B (hepatitis C) was relatively harmless and inconsequential;

taking the decision in July 1983 not to suspend the continued importation of commercially produced blood products;

failing to explain the risk of Factor concentrates and not discussing available alternative treatments, thus treating us without informed consent;

conducting research on us without telling us or our parents beforehand, or informing us of risks and whether the research would enhance our treatment or benefit others. Again, this research was carried out without obtaining proper informed consent and occurred nationwide;

It is more difficult to assess the level of liver disease in the Haemophilia patient than someone without a bleeding disorder. The gold standard test is a liver biopsy which is a dangerous procedure to carry out in Haemophilia patients thereby placing Haemophiliacs at a disadvantage when it comes to assessing the extent of their liver disease.

All of the above are clear examples of the Government's failure to recognise specific issues relating to those with a bleeding disorder.

When the Minister for the Cabinet office, Nick Thomas-Symonds gave oral evidence on 7th May he stated that the Government are *“open to considering how we can improve the Government’s actions to ensure we can deliver justice to victims of this devastating scandal”*. I request that you put the following recommendations to Nick Thomas-Symonds.

It is imperative that a new expert group is formed including Haematologists, Psychologists, Trauma Specialists and a Specialist in liver disease that are aware of the very serious nature of Hepatitis C in its own right, including damage caused by HCV which extends beyond the liver.

The community must also have input into the selection of these experts and must also be included in any agendas which are put to the Experts. Failure to include the community will once again lead to failed outcomes.

Kind regards

GRO-C

Glenn Wilkinson