

Witness Name: David Leadbetter

Statement No.: WITN7765001

Exhibits: WITN7765002 -

WITN7765003

Dated: 29/04/2025

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF David Leadbetter

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 April 2025.

I, David Leadbetter, will say as follows:

Introduction

1. My name is David Leadbetter, my date of birth and address are known to the Inquiry. Before I answer the specific question the Inquiry has posed within its Rule 9 request, I will provide an overview as to how our group was set up.
2. In May 2024, our group did not exist. In fact, on the day Sir Brian's final report was published, I was in a hospital bed, watching Sir Brian's speech on my phone. The report brought a sense of closure in many ways. After so many years of being pushed aside and ignored it felt as if at last we had been heard.
3. However, that joy was quickly extinguished. The setting up of IBCA and how it was being established was something different altogether. I had hoped the report would shape it, after all Sir Brian and his Inquiry team spent years hearing the evidence,

and therefore, really knew what was required. Sir Brian set this all out in his Second Interim Report, dated April 2023.

4. In his statement that accompanied the report, Sir Brian said: *Today's report is the culmination of detailed work on compensation. As you know, the Government commissioned Sir Robert Francis KC to give independent advice on a framework for compensation and redress, so that the Government could be ready for the findings of this Inquiry. The Inquiry has held hearings about it. Most of you who are listening to what I am saying have been fully involved in it, from your different perspectives. Sir Robert and I agree on the fundamentals of the design. Today I recommend that this compensation scheme should be set up now. It should begin work this year.*
5. When the IBCA set out the compensation framework I could not believe what I was reading. I was hoping the Haemophilia Society, or their legal team would be looking out for Haemophiliacs like me. I soon became aware mono HCV infected Haemophiliacs did not seem to have their own cohort and the value of compensation was a lot less than I had hoped for following on from Sir Brian's interim report and suggested compensation framework.
6. At first, I was concerned about ongoing payments stopping in March. I was also grouped together with the whole blood victims. I felt as though something was missing from the scheme but if the compensation amount I would be offered was something I considered to be a fair amount for the life I have been dealt being infected most of my life I would feel compensated.
7. A few days before March 20, 2025, after the IBCA calculator was released, I posted on several Facebook pages I follow, asking if other mono HCV-infected haemophiliacs like me were dissatisfied with the calculations and why. I was overwhelmed by private messages from strangers and familiar haemophiliac victims I already knew. It became clear we needed a private space to connect as a forgotten cohort. On March 20, 2025, I created the "Mono HCV Infected Haemophiliacs" (MHH group) Facebook group, for mono HCV infected Haemophiliacs and their partners/carers. Within 12 hours, it had over 40 members;

within 24 hours, 89 members, a mix of infected and affected victims that all shared very similar feelings.

Please describe the nature of the work which you and your colleagues within MHH group have been undertaking, in relation to the question of compensation, since the publication of the Inquiry's Report in May 2024.

8. I invited others in the group to help with the admin duties, and we locked and hid the group for privacy and security of our members. People were soon sharing stories of how they had stayed quiet, outnumbered by other cohorts and often silenced on social media. We formed an admin team of eight and held our first group call that evening. The connection was instant—we understood each other's struggles and concerns.
9. Within a week or two, we drafted an introduction letter and a template letter to help members share our views along with their own concerns to their MP if they wanted. As you can appreciate, we are new to this so the research we have undertaken is mostly evidence based via what is currently out in the public domain and through the inquiry. Especially thanks to Sir Brian and his thorough and extensive Inquiry he has been able to list points listed below, which has meant that we can focus our work based on the evidence that has been heard and read during the course of the Inquiry. These points are unique to the journey of HCV haemophilic and that have sadly been ignored:
 - 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.

What if any external support or assistance has been, or is, available to you and your colleagues in undertaking the work described above?

10. We have never had any assistance or support before we composed our letter of introduction. We sent our letter of introduction to the Haemophilia Society for their seal of approval and to let them know about us and our approach.

Please describe the involvement of people infected and affected in the decision-making regarding compensation (whether by Government or IBCA or both) as you and your colleagues within MHH group have experienced it.

11. We as a group have not been involved with any of the decision-making and as far as I know none of us as victims were asked for any input into decision-making. The fact that no one has asked us to be involved or acknowledged our presence

or even notice the issues really demonstrates that the HCV mono infected haemophiliac has been forgotten, or worse, that the severity of our infection and the impact on our lives and the lives of our loved ones has been brushed aside as unimportant and “not worthy” of reasonable compensation.

Please describe the principal concerns (if any) which you and your colleagues within MHH group have in relation to the involvement of people infected and affected in the regarding compensation (whether by Government or IBCA or both).

12. When the Expert Group was established, we as the HCV mono infected haemophilia community were horrified to see there was no representation of our community on the panel. We cannot understand why it was deemed unnecessary to include a representative of the group that helped to initiate the Infected Blood Inquiry. How can it be that the shaping of a scheme, 50 years overdue, can take place without the presence of someone that specifically understands what we haemophiliacs have been through.
13. We believe we have been overlooked in the current compensation proposals. I am making this R9 statement on behalf of MHH in the hope of correcting what we believe is a serious miscarriage of justice. At present, our minority group of mono-HCV infected haemophiliacs have been grouped together with the vast number of transfusion recipients. We believe this drastically misrepresents the severity and scale of our losses. HCV infected haemophiliacs were treated repeatedly, not just once but time and time again with contaminated commercial Factor VIII at a time when it was widely known these products were infected with non-A non-B hepatitis and HIV. This was both negligent and reckless. Most of us were infected as infants so have never experienced life without hepatitis.
14. There appears to be a critical misunderstanding that haemophiliacs infected with contaminated blood were co-infected with HIV and HCV. This assumption is wrong and has led to the serious neglect of the mono-HCV haemophilia community. Our infection profile, treatment history, and lifelong harm sets us apart from the wider Hepatitis C group. Our education and careers were

damaged beyond repair. We seek justice for those who have spent a lifetime living with illness, secrecy and disadvantage.

Please describe the impact upon you and your colleagues within MHH group of the matters set out above.

15. We do not have any redress for the wrong doings and systematic failures that were committed by Government. These failures that were picked up by Sir Brian and his Team (please see above) have simply not been recognised for haemophiliacs.
16. HIV-infected haemophiliacs are set to receive up to £29,000 per year, with comprehensive recognition of the systemic failures and lifelong impact. Mono-HCV infected haemophiliacs, by contrast, are offered as little as £6,000. This disparity is indefensible. While we recognise the unique trauma of HIV, it must be acknowledged that mono-HCV haemophiliacs suffered many of the same violations: lack of consent, multiple infections, concealment of diagnosis, lifelong ill health, stigma, loss of career, and in many cases, psychological collapse.
17. We are not transfusion claimants. We are victims of systemic failure and have lived a lifetime with the burden of government negligence and denial, on top of our debilitating disability. We are not asking for a complete rewrite of tariffs, and we certainly do not wish to cause delay.

Please describe the impact you perceive the decision-making regarding compensation (by Government, IBCA or both) to be having on people infected and affected, and why.

18. The decision-making regarding compensation had very mixed reactions but as it stands, we as a group do not believe that many of the MHH group would be happy with their offers made under the current IBCA scheme. The stigma of HIV still follows us around as Haemophiliacs today even though most of us never were infected. The impact of the HCV on Haemophiliacs has not been reflected in the compensation scheme at all.

Are there any particular steps or measures which you consider could be taken by Government, IBCA or both to alleviate any detrimental impact upon you, MHH group and/or the infected and affected communities? If so, please set them out.

19. We simply request that mono-HCV haemophiliacs have a financial core route bringing us in line with the HIV cohort of £29K a year. As set out above, we too have had these childhood issues to deal with as did those with HIV. Most of us have suffered from hepatitis since childhood. We simply want to see parity between the infected groups. This expert group who recommended the tariffs had not been part of the IBI; they had not heard years of evidence and they did not listen to the stories of those of us who are infected and affected. If they had they would never have suggested the tariffs that have been set out.
20. We believe that the Government, IBCA or both need to look at the compensation framework suggested by Sir Brian and use that as the basis for the Scheme. Sir Brian's suggested framework came after the report from Sir Robert Francis had provided his report (commissioned by the Government) and given evidence at the IBI hearings. Sir Brian produced his Second Interim Report having read and heard years of evidence from the infected and affected communities and from expert groups. We do not understand why the Government and IBCA has ignored Sir Brian and we urge them to do the right thing and listen to Sir Brian to ensure all of those who are infected and affected are compensated fairly.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed

GRO-C

Dated: 29/04/2025

Table of exhibits:

Date	Notes/ Description	Exhibit number
28 th March 2025	Letter of introduction for Sir Brian	WITN7765002
4 th April 2025	Template letter for MPs for our members to use if they wish	WITN7765003