

Witness Name: Sean Cavens

Statement No.: WITN1146047

Exhibits:

WITN1146048–

WITN1146057

Dated: 7 February 2025

INFECTED BLOOD INQUIRY

FOURTH WRITTEN STATEMENT OF SEAN CAVENS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 January 2025.

I, Sean Cavens, will say as follows:

Please describe the nature of the work which you have been undertaking, in relation to the question of compensation, since the publication of the Inquiry's Report in May 2024

1. Since the publication of the Inquiry's report in May 2024, I have continued the work that I was carrying out prior to the publication of the report as highlighted in my previous witness statements to the Inquiry.
2. This work has involved submitting Freedom of Information requests, speaking with my MP Ian Lavery so that he can ask questions in Parliamentary debates and contributing to press articles in the Chronicle. I also liaise with other campaigners in Scotland and the rest of the UK who attend meetings with the Cabinet office/IBCA.

3. I have contributed to several press articles in the Chronicle related to compensation since the publication of the report. Seven of these relate to compensation (WITN1146048 to WITN1146054). These highlight the concerns that I have about the involvement of the infected and affected community regarding the compensation scheme, which I will discuss further below.
4. Ian Lavery MP has raised questions on my behalf in Parliament in two Infected Blood debates on 23 October 2024 and 19 November 2024. I have provided the Hansard extracts for these two debates. (WITN1146055 and WITN1146056).
5. On 3 January 2025, I submitted a Freedom of Information (FOI) request to try and obtain further information about operating costs and number of compensation payments made. I received a response to this request on 31 January 2025. (WITN1146057). The response states that the total operating costs incurred by the IBCA as at 31 December 2024 were £15.33 million. I am astounded that the IBCA has incurred this amount of costs in the short time that it has been running, when it has only invited 42 people to make claims. I also still do not understand the selection process for those who are currently being invited to make claims.

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

6. I have had some opportunity to consult my legal representatives about the compensation scheme proposals. However, this has been limited due to the lack of funding that has been provided by the Government. No other external support has been made available to me.

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

7. There has been insufficient involvement of infected and affected people in the decision-making process regarding compensation. There has been a lack of meaningful engagement.

Please describe the principal concerns (if any) which you have in relation to the involvement of people infected and affected in the decision-making regarding compensation (whether by Government or IBCA or both).

8. When the Government has provided information, it has been lacking in clarity and explanation. For example, the announcement in Parliament by John Glen MP, the then Paymaster General, on 21 May 2024 about the proposed compensation scheme, lacked clarity regarding the continuation of support scheme payments and how they would be taken into account in any compensation calculation. I highlighted this in two articles in the Chronicle referred to at paragraph 2 (WITN1146048 and WITN1146049). The confusion surrounding support scheme payments made me feel like the security that I experienced when assurances were given during the Inquiry by Government witnesses that support payments were for life had been taken away. The recent announcement by the Government that, if an infected person dies after 31 March 2025, their bereaved partner will not be entitled to the support scheme payments that they would be entitled to if their partner passed away prior to this date, has caused me further anxiety.
9. There is a lack of transparency about how and why decisions have been made. There has been a lack of information published about the reasoning of the expert group appointed by the Government and chaired by Professor Sir Jonathan Montgomery in fixing the compensation tariffs. I do not think that they have sufficiently taken into account the findings of the Inquiry and its expert groups.

10. There has been a lack of meaningful engagement. An example is the consultation on the unethical research award. There was limited time given to respond to the consultation and nothing seems to have changed in the proposals as a result of the consultation, despite strong representations being made about the inadequacy of the proposals.
11. While we were at the heart of the Inquiry, it feels like we are an afterthought and are now spectators in the process. This goes against the recommendations of the Inquiry, which highlighted the importance of the infected and affected being involved in the process of the design of the compensation scheme.
12. There is a lack of trust as the IBCA say that they are an Arm's Length Body, but also say they have to report back to the Cabinet Office.
13. The feelings of anger, mistrust and the need for increased engagement with the infected and affected community are themes highlighted in articles I have provided from the Chronicle and referred to in paragraph 2.
14. I have concerns about the role of the three user consultants who have been appointed by the IBCA. It was initially advertised as one job, and it was never re-advertised for three people. The role of the user consultants was not clear to me. I contacted the IBCA to seek assurances that the user consultants would not have access to my personal data. I received a response from the IBCA to confirm that they would not have access to my personal information. I also feel that the user consultants who have been appointed are not representative of the community, as none of the user consultants are directly infected haemophiliacs.

Please describe the impact upon you of the matters set out in 1-4 above.

15. When the Inquiry final report was published on 20 May, I felt that the Inquiry had taken the time to listen to us and that we had been vindicated. The recent actions of Government make me feel as though they have not paid attention to

the criticisms made in the report, to the point where I question whether they have even read it. I feel total despair. I feel that I am living in complete uncertainty and in limbo because I don't know when I will be able to make a claim to the compensation scheme. I do not know whether I will be one of the first to be able to make a claim based on length of time since infection as I was infected when I was one year old, or whether I will be one of the last to be able to make a claim because I am aged 43 and therefore one of the younger infected people. I am completely knackered and just want a resolution.

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.

15. I don't think anyone is secure or happy about the situation because we just don't know when and how it is going to be resolved.

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 and/or the infected and affected communities? If so, please set them out.

16. I feel that we are not being encouraged by the IBCA or the Government to have legal support. We rely on our lawyer's advice as they have assisted and advised us throughout the Inquiry process. We need our lawyers to be involved in the meetings and conversations with the Cabinet Office and the IBCA, and for them to be able to then communicate the information to their clients. This would increase trust in the process.

17. We need to be given further information about the timescales for making applications and the order in which the scheme will be opening up applications to different categories of claims, as this would remove some of the uncertainty that we are experiencing.

18. The information published by the Government lacks detail. The updates are not meaningful and often repeat information that has previously been given. No

minutes are produced of the engagement meetings held by the Government or the IBCA. Rather than campaigners having to relay on what was discussed, detailed minutes should be agreed by attendees and published for everyone with an interest to then review. It would be helpful to know what was on the agenda and full details of the discussion, including what questions were asked and the response that was given to the questions. This would allow us to follow up and feed back to the representatives who are attending these meetings on our behalf with questions that we would like to be asked.

Statement of Truth

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

Signed

GRO-C

Dated Feb 21, 2025

Table of exhibits:

Date	Notes/ Description	Exhibit number
21 May 2024	Chronicle article, title "Blood scandal victims to get full compensation 'this year' – but bereaved partners won't get second interim payment"	WITN1146048
21 June 2024	Chronicle article, title "Infected blood campaigners fear they're 'in limbo' and vow to continue fight for fair compensation for NHS scandal"	WITN1146049
6 July 2024	Chronicle article, title "Sir Keir Starmer confirms paying compensation to victims of	WITN1146050

	contaminated blood scandal is 'very important'"	
16 August 2024	Chronicle article, title "Government plans for final Infected Blood compensation published - monthly support payments to continue"	WITN1146051
20 August 2024	Chronicle article, title "Contaminated blood compensation 'still up in the air' say Newcastle and Northumberland campaigners	WITN1146052
24 October 2024	Chronicle article, title "Northumberland MP slams 'paltry' compensation sum for Infected Blood victims used for research as children"	WITN1146053
16 December 2024	Chronicle article, title "Infected Blood compensation payouts to begin amid anger and distrust"	WITN1146054
23 October 2024	Extract of Hansard for 23 October 2024, with contribution from Ian Lavery MP	WITN1146055
19 November 2024	Extract of Hansard for 19 November 2024, with contribution from Ian Lavery MP	WITN1146056
31 January 2025	Response to FOI request dated 31 January 2025	WITN1146057

NOT RELEVANT