Witness Name: Glenn Wilkinson
Statement No.: WITN2050115
Exhibits: None
Dated: 23 February 2025

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF GLENN WILKINSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 February 2025.

I, Glenn Wilkinson , will say as follows:

1. Since the publication of the Inquiry's report in May 2024, Contaminated Blood Campaign (CBC) have been challenging Government on the unfair and discriminatory way they have been dealing with the Hepatitis community in particular. This work has included engaging the opinions of our members, researching and developing evidence and highlighting issues in the press.

2. CBC have also worked with other campaigners and campaign groups on the production of our Infected Blood Compensation: "Getting It Right" document, which has been sent to all MPs, Government departments, the Infected Blood Inquiry and other relevant parties.

3. We have also submitted multiple FOIs in order to gain some understanding of the discussions that have taken place between the Cabinet Office and the clinical, legal and any other experts they have used to validate their decisions relating to the infected Hepatitis community when setting up IBCA. To date,

we have not had any meaningful answers to the very reasonable and relevant questions we have submitted. The Cabinet office have consistently failed to answer the questions in our FOIs to the point where we had to submit complaints to the ICO. There has been and there remains a real lack of openness, transparency and candor on behalf of the Government.

4. We have faced such a profound level of obfuscation that we felt we had little choice but to help promote a legal challenge on the Government's decision-making. This has involved many meetings, hours and days of work, providing evidence and support which has led to a JR pending against the Government. After the highs of the publication of the Infected Blood Inquiry report, we never thought we would need to engage in legal action against the Government, and this is certainly not what we expected nor wanted to do, but sadly we felt we had no choice if we were ever to stand any chance of securing justice for the majority within our community.

5. No external support or assistance has been available in undertaking the work as described above. All of the work undertaken by CBC has been promoted and funded by ourselves.

6. CBC are not aware of anyone infected or affected being involved in the decision-making regarding compensation. It is clear that key decisions have been made by Government and IBCA on our behalf without our involvement. During an online meeting organised by Sir Robert Francis which CBC attended, Jonathan Montgomery made it very clear that the expert group were not set up to hear directly from the people so they did not engage with the community before making decisions on their compensation proposals. This clearly represents a continuation of the paternalistic attitude which was highlighted during the inquiry.

7. Had the Government engaged with our community after the release of Sir Brian Langstaff's Second Interim Report on 5 April 2023, CBC feel the compensation scheme would have stood a far better chance of securing the confidence of the community which would have been ready to roll-out

following the publication of the Infected Blood Inquiry report. Had Government engaged with the community, we strongly feel that most, if not all, of the concerns which have been raised since 20th May 2024, could have been avoided.

8. A key failing relates to the fact that during the online meeting mentioned in paragraph 6 above, Jonathan Montgomery made it very clear that the expert group were not set up to hear directly from the people so they did not engage with the community before making decisions on their compensation proposals. During this meeting I asked Jonathan Montgomery to provide details of the conversations the Cabinet office had with their experts however, he refused to confirm this information would be provided. This is why we made the decision to request this information by submitting a number of FOIs.

9. Following the release of Sir Brian Langstaff's Infected Blood Inquiry report on the 20th May 2024 which vindicated the desperately sad experiences of our community, we were brought down to a "new low" the very next day when we saw the shockingly low levels of compensation being offered to the mono Hepatitis C community, along with the unnecessarily complex criteria involving multiple stages, treatment dates, age of applicants etc which is in sharp contrast to the mono HIV community who only have to prove their infection.

10. Travelling home from London on 21st May, the desperately sad realisation finally dawned that the fight would not end for the mono Hepatitis community. This felt like an utterly gut-wrenching blow, when we were looking forward to being able to start the process of closure and healing and attaining a level of peace whereby we could start to move on with our lives. Instead, we are left feeling that age and illness are catching up with us; there is no rest, there is no peace, we literally live this campaign 24/7 but feel we have little choice but to continue the fight. One of the consequences of campaigning at this level and at this intensity, is that it also has a devastating impact on our home and family life.

11. Although we have had many meetings with Government and IBCA following their decision-making on compensation, we feel these are nothing but a tick-box exercise so they can say they are engaging with the community. They consistently fail to answer key questions, even though we have asked them the same questions multiple times, which leaves us feeling that Government and IBCA are not listening to us in any meaningful way. They consistently trot out what they are doing but they never highlight their failings. We are also often limited in the amount of time we are allowed to speak where we have only been given 4 or 5 minutes. We do not feel this represents proper or fair engagement of this already hugely damaged community. These meetings can be so stressful that I am literally left 'shaking with anger', which has an effect not only on my physical health, but also my mental and psychological health.

12. Although CBC are a self-funding, not-for-profit unofficial body, we still feel a huge sense of responsibility in providing as much information to our members as is humanly possible, this becomes a particular issue as our members do not have the opportunity to attend these meetings to speak for themselves and we are put forward to speak on their behalf. Increasing age and illness of the CBC admin also has a huge impact on the work involved when dealing with Government as we often feel snowed under and suffocated by the amount of paperwork, emails, reports, meetings etc that we need to deal with, and feel re-traumatised every time we engage with Government and IBCA. The fact that all this work rests on our shoulders with no outside support, often leaves us feeling highly stressed and unable to cope with the amount of work we have to deal with. The fact that IBCA and the Government are not providing us with answers to our questions leaves us as the admin of CBC feeling inadequate as we are unable to pass on vital information to our members. This leads to a very deep sense of frustration and depression, I often wonder how we are able to carry on.

13. We feel Government are discriminating against the community based on virus type alone as they wouldn't discriminate based on characteristics such as religion, sexuality or ethnicity as their actions would be described as blatant

discrimination, but they seem perfectly willing to discriminate against us based on the type of killer viruses we have. We feel that Hepatitis victims are being used as a financial scapegoat to undermine Government's financial responsibility towards us. The injustice we feel after decades of campaigning is difficult to put into words. We just feel devastated, sidelined and worn out! Nevertheless, one way or another, CBC will fight to our graves if necessary.

14. On the day of the release of Sir Brian Langstaff's Infected Blood Inquiry report, people were elated to finally feel that everything they had been saying for decades had finally been vindicated publicly however, in the days following the 20th May, the mono Hepatitis community in particular felt deceived and betrayed by Government and its departments. The impact this has had on the community was, and continues to be profound. The huge sense of injustice expressed by our members on our social media platform was, and is self-evident by the many comments that have been posted over many months. They feel disillusioned, confused, depressed, anxious and very angry. Most people feel betrayed by the Government proposals, expressing the fact that the proposals are certainly not what people expected after many decades of fighting and after a six year Inquiry.

15. The following is taken from page 3, paragraph 1 of our Infected Blood Compensation: Getting It Right document, which describes how the Government have shied away from key issues and also the lack of time available to consider and deal with these very important issues.

"The Government have shied away from publicly admitting to rejecting key inquiry recommendations, relying instead on inaction or different action to show what it is not supporting. This has been possible in part due to the Parliamentary timetable being greatly restricted once the General Election was called just two days after the Inquiry Report was published. This automatically included the proroguing of Parliament for several weeks resulting in a complete absence of oversight and scrutiny when important infected blood matters were being taken forward. Elected members could not advocate for their constituents or the relevant representative interest groups.

The committee system could not hold Ministers to account, so for a crucial period of weeks there were not the usual parliamentary checks and balances."

16. In Sir Robert Francis' Recommendation Summary to Government report of August 2024 in his Executive Summary he states

"*This engagement exercise and report is imperfect. Very little time was made available for undertaking this work. It was severely limited by the time required to prepare the regulations needed to set up the scheme by the deadline of 24 August set by Parliament. The extent of the engagement permitted has also been constrained by long-established restrictions on what it is possible to publish during a pre-election period. I regret that*"

and on page 23 of the same report he states under the heading Distinction between HIV and HBV/HCV

"Some comment has been made to the effect that as HIV is not subject to a severity banding, neither should HCV and HBV. This is not the view of the expert advisory group, and their reasoning for adopting a different approach for each infection is based on their understanding of the progress of each disease, and therefore, seems to me to be a reasonable justification for accepting their recommendations. Had there been a longer period available for engagement, it would have been preferable to test that advice against a wider range of lived experience and indeed to engage with a wider group of experts."

17. We don't need to look far to identify the reasoning why our community feel disenfranchised and angry with the Government's decision-making. Sir Robert Francis' statements in paragraph 16 above describe the expert advisory group's apparent reasoning for the different approach between HIV and HCV/HBV and therefore he believes the severity bandings applied to those with HCV and HBV seem reasonable to him. What Sir Robert Francis fails to mention is that the community have never been given the opportunity to engage with anyone within the expert advisory group, either pre or post

their decision-making, nor have we ever been given sight of any specific discussions that have taken place between the Cabinet Office and their expert advisory group on this specific topic, or indeed, any other matter. The Government/Cabinet Office themselves chose all the experts, with the community being left out of all decision-making, even the identities of the experts were initially withheld from us. All the community have been given are general overviews of what the experts are supposed to have said and we are expected to accept this, presumably on trust? Because of the heinous actions of Government, including the fact they are directly responsible for infecting and killing thousands of their own citizens, trust between the community and Government is none existent. Sir Robert Francis hasn't even confirmed whether or not he was in any way privy to specific relevant details of any of the engagements between Government and their experts. Sir Robert may be willing to accept the narrative as described by Government in terms of the engagement with their own chosen experts and what their experts are supposed to have said, but that certainly doesn't mean the community have, or ever will, accept it. How can the community accept or indeed not accept what they have never seen? Sir Robert Francis himself accepts there was a lack of time and engagement with the community and a wider group of experts however, nowhere in his report did he recommend that views of the lived experience of the community and further experts be sought at any point in the future. He has effectively abandoned the Hepatitis community to a failed compensation scheme. Sir Robert's report highlights clear anomalies between what the community should have been reasonably able to expect compared with the failure of the process to deliver fair and equal compensation. The evidence is out there, however Government have cherry-picked from the available information to serve the narrative and keep costs down.

18. CBC and other fully inclusive campaign groups feel a very real sense of abandonment by many within the HIV community, including certain support/campaign groups. There have been no initiatives taken by anyone within the HIV community that I am aware of to publicly highlight specific Government failings in terms of the mono Hepatitis community. The feeling

is that the majority within the HIV community don't want their 'boat to be rocked' and that they are simply staying quiet while waiting for their very large levels of compensation to be paid. We also feel that some of the official organisations including the Haemophilia Society are paying lip-service to raising our issues, and as a Haemophiliac myself, this has come as a huge disappointment. We feel that some of these official organisations are keeping quiet on specific issues relating to the mono Hepatitis community as we believe they are concerned that the Government may not provide them with the funding which they hope to receive. This has caused dissention and conflict at a time when Government should have done all they possibly can to create cohesion and harmony within the community.

19. When Government stand up in the House to highlight the progress they are making, the feeling within the community is that they are being 'gaslit' as the statements made by people such as Nick Thomas-Symonds bear no relation to what is actually happening on the ground. The Government are clearly spinning a false narrative to try and justify the decisions they have made without the community's input. The frustration and anger this gaslighting produces within the community is hugely damaging. This ongoing scandal is simply heaping injustice on top of an already decades' long injustice, which in itself needs to be independently investigated.

20. The lack of detailed information subsequently provided by Government and IBCA has only served to compound these negative feelings. It has been very clear and very sad to witness the impact on people's mental health and deterioration in their overall health.

21. In conclusion, the community expected to be able to move on from this scandal following the publication of the Infected Blood Inquiry report. Although this will be possible for many within the HIV community, this will certainly not be possible for the majority within the mono Hepatitis community as the proposals will only serve to re-traumatise them for years to come. Considering the mono Hepatitis C community are dying in the greatest numbers as clearly shown on page 87 of the Inquiry's statisticians report

when compared with the mono HIV and even the co-infected HIV communities. Government proposals are clearly designed to under-compensate some of the most vulnerable people within our community which is utterly shameful! CBC have acquired further information under FOIs to IBSS which correlates with and expands on the evidence provided by the statistician experts. The Hepatitis community in particular feel that the Governments' proposals do not represent restorative justice and that Government could not have created a more complex and discriminatory scheme if they had tried.

22. Those who have been given a terminal diagnosis should be prioritised for compensation with immediate effect. CBC have consistently been asking for Government and IBCA to provide an on-line calculator, setting out the detail of the compensation individuals are likely to receive; however, no calculator has yet been provided. Also, official flow-charts would be useful to the community to show the process which will be needed to navigate the route to compensation. We have no doubt that flow-charts would identify the hugely complex process required to navigate the route to compensation for the mono Hepatitis cohort whilst at the same time, identifying the far more straightforward, linear and stress free process required for the mono HIV cohort. CBC are in the process of producing our own flow-charts, the first drafts of which are already highlighting the very clear disparity between the extremely complex and onerous processes needed to apply for compensation through the Core route for the mono Hepatitis C community compared to the very straightforward and linear process required to apply for compensation through the Core route for the mono HIV community.

23. CBC members have been consistently asking for a timescale setting out when they can expect to receive their compensation so that they can manage their financial affairs. No timescale has yet been provided by Government or IBCA. However, we do know the following: Government and IBCA recently announced there will be various stages in which individuals will be able to apply for compensation. There are six stages in total, which include 1. Living Infected already registered with a support scheme; 2. Supplementary claims;

3. Registered estates; 4. People who are affected and are linked to a registered infected person or registered estate; 5. People who are infected but not registered with a support scheme and 6. Personal representatives applying on behalf of an estate that is not registered with a support scheme. This, combined with the complex and onerous multiple stages and criteria being applied to the mono Hepatitis community will mean that compensation will take years to fully roll-out to everyone, which is probably why Government have stated a lifespan of 7 years for IBCA.

24. In Sir Robert Francis' Recommendations to Government report of August 2024 he states the following on page 38 regarding Punitive Damages

"I have been reminded that in the Framework report, I suggested that the position with regard to punitive or exemplary damages should be revisited in the light of the findings of the Inquiry report. It has been submitted that the findings now published include criticisms on which a claim for such damages could be mounted. I note that the Inquiry report does not make recommendations in this regard. I note, however, that the Horizon Group Litigation Order Compensation Scheme does in certain circumstances allow for an award of exemplary damages – of £75,000 in the case of unsuccessful malicious prosecution. Under that scheme, each case is to be considered on its merits."

Sir Robert then goes on to say:

"I am unable to recommend such an addition to an already complicated scheme."

25. It needs to be remembered that it is Government themselves that have created this 'already complicated scheme' and that it should have been the community themselves that were part of the decision making process in terms of punitive damages. However, we were never consulted on this important issue.

26. As Sir Robert Francis correctly identifies the findings published in the Infected Blood Inquiry report, includes criticisms on which claims for punitive damages could be mounted, it must therefore be the decision of individuals within the community to decide for themselves if they wish to claim punitive/exemplary damages and **not** the Government.

27. When the five solicitors wrote to Sir Brian Langstaff on 4 December 2024, at item 1 they said

"The most fundamental problem with IBCA is that it is not an Arms Length Body (ALB) as you recommended; most if not all other problems, flow from the Government's failure to adhere to Recommendation 14 of your Second Interim Report."

and at item 2 they say:

"the IBCA is not only not an ALB, it is the antithesis of one. The IBCA operates under the direct control of the Cabinet Office, is dependent upon the Cabinet Office for staff and funding and is directed by a Cabinet Office Policy Team. The Board of the IBCA is staffed almost exclusively by civil servants, most of whom we understand to have been procured from either the Cabinet Office or Treasury."

28. CBC wholeheartedly agree with these statements. The Government should apply Sir Brian Langstaff's Recommendation 14 with immediate effect.

29. Over the years the Government have and continue, to apply hard cut-off dates to Hepatitis C victims. No hard cut-off dates apply to HIV victims thereby creating a further ongoing disgraceful anomaly. Government can and should immediately change the eligibility criteria for IBSS and remove the cut-off dates for Hepatitis C victims. We have raised this issue many times with Government and they have said qualifying applicants will be able to apply for compensation through IBCA which can be paid in periodical payments however, this will not allow those that have been unable to join the IBSS

schemes due the strict cut-off date criteria to join, before compensation is paid. This has two clear disadvantages; firstly, compensation may take many months and probably years to sort out which will leave these people without any compensation or regular support before their claim is dealt with and secondly, as those that are currently registered with the IBSS schemes have the opportunity to continue to receive their regular support for life, this will not be possible for those described above.

30. In conclusion, Government can and should immediately change the eligibility criteria and remove the cut-off dates for Hepatitis C victims. Like Hepatitis C victims described in paragraph 29 above, Hepatitis B victims have never been recognised through the IBSS schemes therefore they will be in the same situation regarding compensation and receiving regular support for life. Government should immediately change the eligibility criteria to include Hepatitis B victims.

31. There is no doubt that the criteria and process being applied to the mono Hepatitis community is unnecessarily overly burdensome and complex, which the Inquiry specifically recommended should not happen. The Infected Blood Inquiry's recommended tariff system is being used by Government to unfairly under-compensate the mono Hepatitis community.

32. While it remains a fact that stages can be applied to any medical condition, it is clearly anomalous to apply further stages to Hepatitis C while at the same time applying only a single stage to mono HIV, particularly as under the current IBSS schemes, mono HIV beneficiaries are paid the same annual payment as mono Hepatitis C Stage 2 and mono Hepatitis C SCM beneficiaries. The hugely onerous and unnecessarily complex stages and criteria being applied to the mono Hepatitis community will mean that it is going to take years to deal with those claimants. In this context, I am reminded of the often used phrase through the Inquiry, 'justice delayed is justice denied'.

33. The complexity and unfairness within the Government's proposed scheme will mean that the time it will take to deal with mono Hepatitis claims will lead to huge delays thereby denying this cohort access to compensation in a fair and timely manner. This will also mean that a large number of mono Hepatitis C beneficiaries registered with the schemes will more than likely decide to carry on with their IBSS payments rather than wade through the endless complexity and uncertainty of the compensation scheme; which will effectively mean the mono Hepatitis C community will not receive the Lump sum compensation they need and deserve. This will also meant those continuing on the support schemes will feel 'shackled' to a Government sponsored support scheme which is the same Authority that was responsible for infecting us in the first place, which has already killed thousands within our community and which will continue to do so. We will effectively feel unable to 'break free' from our abuser. This is beyond unacceptable.

34. In conclusion, the overly burdensome and complex criteria being applied to all mono Hepatitis victims should be removed with immediate effect. This would allow a much fairer and straightforward compensation scheme for the majority, which would also vastly speed up the process needed to deliver compensation to both the infected and affected communities, as the removal of stages and criteria would significantly cut down on the amount of time and manpower needed to assess all Hepatitis claims. CBC have carried out research which would offer a swift and much fairer solution to the compensation model as currently set out by Government. This will involve removing the unnecessarily complex, onerous and discriminatory stages/criteria being applied to all infected mono Hepatitis victims. Government have committed 11.8 billion in the budget for compensation and they have also said they will pay 'whatever it takes'. CBC are aware that there are approximately 3,545 living infected beneficiaries of all cohorts registered with the four UK IBSS schemes. If the full cohort of 3,545 were paid a minimum of 2.4 million (an average figure which we believe has been allocated to the mono HIV cohort) through a revised Core route, (which would total approximately 8.5 billion) this would not only allow the majority of infected individuals to receive their compensation without going through the

torturous process of applying through the current IBCA model, it would also mean the vast majority would choose this level of compensation as opposed to staying on the schemes, this would also allow us to become free of our abuser. For those that feel they won't be fully compensated through our proposed Core route model, a revised and fairer Supplementary route should be the option. CBC's suggested model would allow IBSS to make payments to every infected person registered with their schemes within days, if not weeks, thereby drastically reducing the length of time it would take to compensate all the remaining cohorts listed in paragraph 23 above, who could then be processed far sooner than would otherwise be the case. This solution would remove the bottleneck of infected claimants registered with the schemes as well as the need for IBCA to hire several hundred staff which would be required over the next 7 years to deal with the complexity of the Government's current compensation model. This would also have the benefit of speeding up the process for Estate claims as they would not have to prove which specific stage their loved one was in. This would also remove the need to deal with the many potential court actions that will no doubt be forthcoming from beneficiaries who have been denied their right to meaningful compensation. The overall benefit of this model would be that both the infected and affected would stand a far better chance of being compensated before they die. If Government fail to do this, it will mean our community will have to wait many years for these time-consuming and onerous assessments to be carried out, which will mean many more people will die before ever receiving the compensation they need and deserve. Too many people have already died without seeing justice.

35. It is widely accepted that Government have completely failed to deliver a compensation scheme which would have secured the confidence of the community. These failings have had a devastatingly negative impact on our community which has been going on since the day after the release of Sir Brian Langstaff's second interim report in 2023. It is for this reason CBC are calling for an investigation into what we consider are the deplorable actions of Government because of their failure to properly engage with the community in order to deliver none discriminatory and fair levels of compensation.

<u>Statement of Truth</u>

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

GRO-C

Signed ____ ______________________________

Dated ______________23rd February 2025______________

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**