Witness Name: CAROLYN CHALLIS
Dated: 5 February 2025
Statement No: WITN0622013
Exhibits: WITN0622014-15

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CAROLYN CHALLIS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 January 2025.

I, Carolyn Challis, will say as follows:

1. This is my third statement to the Infected Blood Inquiry (the Inquiry). As set out in my previous evidence, I was infected with Hepatitis C during treatment for cancer between March 1992 and July 1993. Despite clear evidence from my treating doctors that blood transfusions I had been given were the cause of my infection, both the Skipton Fund and EIBSS rejected my claim for support due to the September 1991 cut-off date. I appealed the decision from EIBSS however it was maintained. This was confirmed in a letter from EIBBS dated 17 June 2020 which stated:

   "It is the evidence of your treating doctors that you were infected with hepatitis C as a result of the transfusions received during 1992 and 1993. While the Panel accepts the evidence of your treating clinicians, it has no power to vary the 1 September 1991 date. In light of the fact you contracted hepatitis C after September 1991 outside of the Scheme Rules, the Panel has no power to grant your appeal. Accordingly, we regret that we must refuse your appeal."

2. In Sir Brian's Second Interim Report dated April 2023, he recommended that the cut-off dates should be removed from the scheme without exception. In his final report dated 20th May 2024 he recommended that in order to find the undiagnosed, those who had received a blood transfusion before 1996 should be offered a hepatitis C test. This led to a change in the guidance on the NHS website.

3. The Infected Blood Compensation Authority (IBCA) maintains that in the new compensation scheme there will be no hard cut-off dates.

4. In the meantime, the EIBSS eligibility criteria remain unchanged, meaning the September 1991 cut off date is still being enforced. This inconsistency has left my cohort confused, in limbo, frustrated and anxious, as we are still unable to register. Are the cut-off dates gone or not? As Sir Brian has said in his final report, the infected blood scandal was not an accident. In cases like mine, where stocks of unscreened blood were still being used after screening began, the negligence is even more stark. They knew the blood was risky but carried on regardless. I am almost 70 years old, and I have been fighting for inclusion since 2004 when I was rejected by the Skipton Fund because of the timing of my infection.

5. We are living infected, yet we are denied all financial and psychological support, and our lives are ticking by fast. We've gone from the euphoria, hope, validation, vindication and relief of hearing Sir Brian deliver his final report in May 2024 to despair, anger and frustration, as nothing has changed for us. Several campaign groups are persistently advocating on behalf of the cut-off date cohort, yet their calls for change have so far fallen on deaf ears.

6. We do not have time on our hands. Unless the government intervenes swiftly to advise EIBSS to remove the cut-off date criteria, we will lose the opportunity to register before the 31 March deadline. If we can't register with EIBSS it seems that we will also be denied the choice of support payments for life, which is another massive loss. We have never received interim payments or a penny of financial support.

7. The official minutes (**WITN0622014**) from meetings with James Quinault, Director-General at the Cabinet Office and various campaign groups, in January this year state that:
   "A specific question was whether people in these circumstances will receive backdated support payments as part of their overall compensation package. People in this situation will not receive backdated support payments but individuals who are or were infected with a chronic case of Hepatitis are eligible for compensation under the Infected Blood Compensation Scheme and this includes compensation for past financial loss and care costs".

8. This would appear to be discriminatory. We just want equality with everyone else. At the moment I cannot even access much needed psychological support.

9. I am in contact with several others in my cohort who, like me, are experiencing increasing anxiety and distress, causing a decline in their mental health due to this ongoing exclusion and marginalisation.

10. Since the publication of the Inquiry's report in May 2024, I have repeatedly contacted Sir Robert Francis, the IBCA, the Cabinet Office, Nick Thomas-Symonds, Wes Streeting, the DHSC, and others to highlight our concerns. The responses I've received have been disappointingly generic and formulaic, offering little meaningful information. I know that many others in the community share my frustration. It's exhausting and demoralising.

11. We should not need to be campaigning still! People are so very tired and unwell, and they feel the government is laying trauma upon trauma with their delays and intransigent manner.

12. I have been networking with campaign groups including Contaminated Blood Campaign (CBC), Blood Loss Families, Blood Friends and the Scottish Infected Blood Forum. I have not been invited to any of the meetings with officials from the Cabinet Office or the IBCA, , so I try to make sure that the

campaign representatives who do attend ask questions on behalf of my cohort. They have all been brilliant. I am in constant contact with friends and campaigners across the community, and we all work together very closely. I have also given many media interviews, including one last week to the BBC which will focus on the delays in rolling out compensation, and on the so far excluded groups.

13. There is no external financial, legal or psychological support or assistance available to us. We have been left to support each other. We are all waiting for some kind of closure. As yet we are unclear as to what level of legal support might be on offer, as and when we are "invited" to make a claim. It seems, based on the feedback from those already invited, to be minimal. It also appears, as reported in The Telegraph on 2nd February of this year (**WITN0622015**), that the legal teams involved were at one stage asked not to share negative feedback with the press, which surely amounts to a gagging clause? Furthermore, I understand the IBCA has contracted the services of a PR company, at a cost of £250,000, to try to promote a positive image, in a move to improve public perception. In my opinion they would be better served addressing the issues that are causing any negative press rather than wasting money in this way.

14. I understand that currently, the IBCA is inviting individuals to apply for the Scheme as part of a 'test phase'. Of those invited so far, all have been living infected individuals who are registered with the existing support schemes. I cannot see how the Scheme can truly be tested unless individuals from all groups within the community are invited, including those who have so far been excluded such as those in my cohort.

15. In my experience, the involvement of infected and affected people in decision making has been totally inadequate. It seems to be simply a tick box exercise where nothing changes despite our pleas. Our questions go unanswered or we receive a copy and paste reply; we are faced with platitudes, deflection or are just ignored. The IBCA have taken to sharing information and updates on

social media, however no replies are provided to the comments on these posts and so this can hardly be described as engagement. Although updates are also sent out by email, these say very little. The overall feeling is that the government is deliberately dragging its heels and does not care about us.

16. From the Webinars I have attended I can see that Sir Robert Francis, David Foley and the wider IBCA team appear to listen with compassion and understanding, but they have no power to change the regulations, only to administer them. Every time an issue with the actual terms of compensation comes up, they say they will need to pass it back to the Cabinet Office, who appear to be pulling all the strings and to be in control of everything. Sir Brian recommended that the compensation scheme should be delivered by an arms length body. I suspect that the way that the IBCA is operating is not what he had in mind.

17. Of great concern regarding the involvement of people infected and affected in decision making is the stark lack of transparency and candour. We have not been properly consulted, or asked for our experiences, and the decisions have been made behind closed doors and without taking into account the recommendations of the Inquiry or the conclusions of the Inquiry's expert groups. Freedom of Information requests about what is happening behind the scenes are blocked or delayed, meaning we are often left in the dark. We're in this place of disillusionment, conflict and despair now simply because the government failed to consult properly, and therefore began with a flawed system.

18. Recently IBCA put adverts out for a User Consultant role. Only one job was advertised: it was a full time position which involved working in Newcastle on certain days. Most of us felt that due to our health we would not be able to work these hours and travel so regularly to Newcastle. We subsequently discovered that three applicants were asked to job share and all were given the option of working remotely. Had others known that these terms would be on offer, many more would have applied. Of the three User Consultants appointed, not one has personal experience of infection via a transfusion.

19. Those working for IBCA on the phone lines know very little about our conditions, about the history of infected blood, and crucially about the new scheme. People are being told one thing one day and something different the day after. Our experience of living with the effects of infected blood is not being taken into account; we are being shut out of the process. This has caused many to lose even more trust and hope in the new scheme.

20. The impact of the delays on the community has been devastating. We're suffering from compounded trauma, anger, frustration, exhaustion, and a loss of hope. We're experiencing an even further decline in our physical and mental health; I have heard several reports of individuals who feel suicidal. We don't feel heard, and it's as if there is contempt towards us. We have been left confused by conflicting and incorrect information and moving goalposts.

21. In May 2024, when we were all radiant with hope and euphoria after hearing the Inquiry Final Report, we felt heard, validated and vindicated. We were also relieved to be told the next day, by the previous government, that they had a plan: they would deliver justice and they would work at pace! Then the very next day they called an election and burst our balloon of hope and optimism and our high spirits were crushed. We felt betrayed and lied to. Since then there has been more trauma than ever before inflicted upon us. We have struggled for decades with our health, our losses, stigma and never-ending campaigning. We've felt ignored, gas-lit and lied to by the government before, but this is on another level. This is laying trauma upon trauma. It is compounding the harms. We deserve better.

22. Despite the IBCA confirming that there will be no hard cut off dates, there has been no mention of how or when my cohort and other excluded groups will be able to apply to the new scheme. We cannot plan for the future, or begin to find any kind of peace and closure. There is no timeline, and this is causing hurt and confusion for the whole community.

23. Many of the infected are very unwell now. On average two people die each week from the HCV infected community. Tragically they will join all those that have gone before them in dying without justice.

24. Since the proposed tariff table was published shortly after the final report, yet more harm and division has been inflicted on our community, due to the lack of parity between the tariffs for mono HIV infected and mono HCV infected. The financial losses for the Mono HCV infected have been discounted to 40% of average earnings (as if we could work 3 days a week), as compared to mono HIV infected who will be awarded 100% of average earnings with no questions asked (which they absolutely deserve).

25. Why is the government doing this we might ask? One can only assume it's because there are far more of us. It's certainly not because HIV is more deadly. At the present time HCV is the killer virus as two of our community lose their lives to it each week.

26. The HCV community will need to go through the supplementary route to obtain anything like a fair compensation amount. This will mean jumping through hoop after hoop to prove once again how unwell we are and have been, digging up old traumas, and searching for medical evidence which may well not exist. Many extra hepatic manifestations will be hard to evidence. Most of us suffered in silence, having been fobbed off by doctors, or left mistrustful of the medical profession (we'd been poisoned after all!) and most will struggle to prove their cases.

27. For me personally, I never knew from one day to the next how I would feel, and so was unable to work. I had to endure repeated DWP work capability assessments just to get my benefits, and now it feels as if I will have to do the same thing again. I had to be pulled off the damaging interferon and ribavirin treatment which so many of us had, and which left lasting damage to our bodies. I remember vividly the nightmares from that time, it's the closest I have ever come to looking over the edge of the abyss. In my mind HIV, HBV and HCV are all life-changing, life-threatening, debilitating viruses, capable of

killing any one of us infected. Infected is infected, dead is dead. Why are some of our lives worth more than others?

28. To alleviate the detrimental impact on the community, the Government and the IBCA need to start listening and responding to the concerns of infected and affected people, and to make the relevant changes. They need to act more quickly and with greater transparency and candour, as promoted by the Prime Minister Sir Kier Starmer.

29. Rather than spending money on PR they need to fix the issues that we have been complaining about for months. We need proper financial and legal support and a clear timeline for when payments will be made to all infected and affected.

30. The powers that be must register with haste all so far excluded living infected individuals. This should include those infected after the cut off dates, those infected with HBV, those with missing records and self-clearers. It is not our fault we were infected a little too late, or with the “wrong” virus, or if hospitals lost or destroyed medical notes. We should be offered the choice of support payments for life, just like everyone else.

31. Above all else there should be parity and fairness in the tariffs across the community, and more speed, genuine engagement, candour and transparency in the rollout of compensation. We don’t have time or the energy to keep fighting for justice.

Statement of Truth

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

Signed : GRO-C

CAROLYN CHALLIS

Dated : 5 February 2025