Witness Name: Samantha May
Statement No.: WITN0912009
Exhibits: WITN0912010-11
Dated: 7 February 2025

INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF SAMANTHA MAY

I provide the statement in response to a request under Rule 9 of the inquiry rules 2006 dated 17 January 2025

I, Samantha May, will say as follows:

Section 1: Introduction 1.

1. My name is Samantha May, my date of birth is known to the Inquiry. I live in London. My address is known to the Inquiry.

2. I have worked full-time as the Helpline Information and Support Service Manager for The Hepatitis C Trust ("the Trust") since July 2004.

3. Our Helpline Support and Information Service has been running since July 2004 to help support, guide and inform all those infected or affected by hepatitis C (HCV), regardless of route of transmission.

4. We previously provided a written statement in September 2021 and oral evidence in March 2022 and a second written statement dated August 2nd 2023.

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

5. Since the final report of the inquiry, we have been working with the community to try to enable individuals to navigate their way through this incredibly complex and, what appears to be, a very secret process. We have held two webinars for the community; the first, in October 2024 attempting to decipher complex but critical information for the community and the second in January 2025 for the community to hear from the Infected Blood Compensation Authority (IBCA) directly about their current plans. Collectively to date around 2900 people either attended or later watched these two events online.

6. In addition, we have held two smaller and more informal group meetings for the community to address IBCA directly with 26 people attending in total and another is scheduled for 17th February 2025.

7. In addition, we have held **10** support groups since June 2024 to enable the Community to be able to discuss and explore this with each other and with us in a friendly, informal, confidential and supportive space with 130 people attending in total – another of these will be held in February, date to be confirmed.

8. One focus has been to try to help to remove the complexity of government documents to provide a more user-friendly context to assist people on our helpline, in bulletins, in groups and through social media channels. However, because of the sheer volume of telephone calls we are receiving about the scheme, which is happening as a direct result of the way in which the Cabinet Office (CO) is dealing both with this process and the community, it has been incredibly difficult for us to be able to review fully the government documents because we have not had the time. This means that we have been unable to provide full and detailed information to the Community.

9. We have answered thousands of calls, including from people across the world, regarding the interpretation of compensation, accessing the blood support schemes before they end and more general information since Sir Brian produced his final report and the compensation process was announced.

10. In addition, we practically support people, both newly diagnosed in applying to the IBSSs for the first time, those that had tried before and failed (dating back to previous Skipton Fund/BSS applications from 2004 onwards), those previously unaware they or their family members were even entitled to claim until the publicity surrounding the report of the Inquiry and since. We have heard from 28 newly diagnosed people since May 2024. Before the final report of the Inquiry we usually heard from 2 newly diagnosed individuals per month; since the final report we have heard from 3 newly diagnosed individuals per month.

11. We also support those who had received payment from the Skipton Fund but had not been notified when the schemes changed. They were completely unaware of the change to EIBSS, WIBSS, SIBSS and NIIBSS. We assisted them to release their paperwork from the lawyers holding the paperwork from The Skipton Fund and then to make a claim to the new scheme.

12. It is often a time-consuming process for both us and the community guiding people through all the options for gathering the evidence they need for a successful claim, including directly assisting them where help is needed to complete the forms and providing step by step guides on what is required and how to best illustrate their situation, often with limited records, for the best chance of a successful claim.

13. After people have struggled through that process, sometimes only to be turned down, they then go on to appeal, and often, the appeal is refused, they think what can I do now? Their only option is to come to us at the Hepatitis C Trust, our helpline workers and volunteers have to emotionally support individuals throughout this process, which includes managing their

feelings of frustration, disbelief at the system after what has happened to them, panic about not being successful and disappointment if turned down and the distress that in turn they may not be included in the compensation scheme, or if they are, they will face a long wait for the situation to be resolved.

14. Over the past few months it seems to be harder than ever to be accepted onto a support scheme. We have heard from people with really strong cases turned down by EIBSS. And there is now the added pressure of the 31st March deadline. One person was told her appeal has to be in by the 31st March; I do not know where that leaves people who are only beginning the process now for the reasons outlined above.

15. Many in the whole blood community are relatively "new" to all of this – whereas those in the bleeding disorder community were typically diagnosed early, and in the main, mobilised as a supportive, informed and engaged community throughout the decades of campaigning and research they have undertook. They are usually regularly monitored by health professionals for their bleeding disorder and other conditions, for example within haemophilia centres, whereas many of the whole blood community have been unaware for decades that various physical or mental health conditions they were developing, were connected with an HCV/HBV infection they often didn't know they had, and so may not be clearly documented.

16. In addition, we are trying to provide basic calculations of compensation for incredibly anxious claimants who find the regulations relating to the scheme overly complicated and incomprehensible. These individuals are trying to follow the regulations to try to work out what, if any, compensation they might be eligible for if/when they are accepted on a scheme. Some of these individuals do not have sufficient funds to be able to look after themselves and their families whilst waiting to receive money from the compensation scheme. In addition, some people have made unwise decisions, following interim compensation payments because they believed the government would set up a compensation scheme as a matter of urgency, and deliver

payments swiftly, which is causing additional practical and emotional problems for them now.

17. As a staff team, we are continually having to work extended hours to accommodate and respond to often very distressed, confused, angry and tragically, sometimes sick or dying people. We are having to take detailed histories of people's lives to try to ascertain whether they or their loved ones had a transfusion, or likely had a transfusion. Often this is a hugely sensitive process trying to piece their story together and draw out information that is often highly emotive. Many people are elderly, or in ill physical/mental health and it often takes considerable patience and time to explore all of this effectively. It will be no surprise to the inquiry, or to the government, that this is a very complex issue due to the fact that so many records have been destroyed. As time moves on trying to establish where, when and why individuals had a blood transfusion becomes increasingly difficult, if not impossible.

18. In addition, we are dealing with a huge influx of people who have never been tested for HCV despite having had one or more multiple transfusions pre 1996, in some cases going back to the 1960s. We are supporting them to access testing, and treatment if actually diagnosed, as well as having to explain the enormity of their diagnosis in relation to access to the IBSS's and compensation, the history of infected blood and the work of the Infected Blood Inquiry – all of which leaves people in complete disbelief and overwhelmed – on top of the fact they have just been diagnosed with a serious and life-threatening illness.

19. Since the publication of the Inquiry's report in May 2004, we have seen much complex information and regulations pumped out from the CO. Under the new scheme it is clear that individuals with Hepatitis C will have to evidence each part of their treatment and care which means the evidence that has to be provided goes over and above that evidence that was required in relation to the IBSS schemes and very likely the special category mechanism (SCM) although we don't have that information yet.

Individuals will have to provide evidence of every stage of their hepatitis along with details of all health conditions and dates.

20. Given the paucity or lack of records it is impossible at times for individuals to provide that evidence. We appreciate that the advice workers at IBCA state they will assist individuals, but the fact that IBCA requires so much more evidence and, for many individuals, the issue arose such a long time ago I simply do not believe, based on the evidence we heard throughout the course of the Inquiry, that claims managers will be able to find evidence from the 1960s onwards through official records and once again it will be the responsibility of the individual to obtain whatever alternative evidence they can.

21. For the whole blood community their Hepatitis C diagnosis often took decades, and often there is no clinical evidence in relation to progression of Hepatitis C, because the diagnosis has been so delayed. That is what is so concerning; individuals are very concerned about how they are going to prove their case in the face of such a lack of information.

22. One example of this is in relation to one of the individuals within the group of 25 being assessed by IBCA at this time. That individual may have to evidence his work record from decades ago if he decides to go down the supplementary route. The claims assessor, who had previously worked for HMRC, was not willing to follow this up on his behalf, saying it would take "a long time on the phone", so he decided to go ahead to obtain his own records and therefore, contacted HMRC himself. Even after contacting HMRC, he was unable to obtain the records. Eventually, he had to complete a Subject Access Request (SAR) to get his records. This is not a simple process and took several weeks and is an example that indicates that staff at IBCA do not seem able to assist claimants to obtain records as they have advised they will do. How long will it take to process all of the claims from the infected and affected community, and what happens to the people who are ill or infirm or simply unable for a wide variety of reasons to seek evidence for themselves? Please see attached ***Overview of***

experience of IBCA process shared with us by one of the original 25 people randomly selected (WITN0912010)

23. If an individual was able to get onto EIBSS the process was then usually straightforward to apply for a Special Category Mechanism (SCM). In relation to SIBSS, applicants were just required to fill in the form and it was accepted. It has always been more unusual for us to speak to SIBSS, WIBSS and NIBSS claimants, we believe because the process of those organisations is easier to navigate and understand they assist individuals through the process more. With EIBSS, the majority of claimants need hard clinical evidence and support through the process - but even with our help, sometimes those claimants are not always successful. The process is not fair.

24. Since the publication of the Inquiry's final report and the information and regulations in relation to the IBCA and compensation scheme the impact on individuals has been huge, both on staff and volunteers at the Hep C Trust and for infected and affected individuals. We have been dealing with newly diagnosed individuals and the existing infected blood community. I can confirm that the distress and confusion of both those groups, by which I mean ranging from an individual that has been newly diagnosed, to somebody who is well versed, engaged and has been campaigning about the issue for 30 or 40 years - the distress and confusion for everyone in the community is off the scale. And like nothing we have heard or seen before.

25. Individuals are seeking our help continually, and we are doing our best to try to explain the situation to them, and in some cases, literally hand hold people, step by step. However, we do not have the infrastructure to enable us to do this efficiently and quickly. We do not have the funding to employ more staff, which would be a lifeline, to work on the helpline to enable us to respond to people much more quickly.

26. We do not have sufficient staff to allow us to find the time to read all of the complex information being pumped out from the CO, digest and reframe it more simply and that means that it is even more time consuming and

difficult to guide people through the expected process. I attach a graph that demonstrates the increased in telephone calls to the helpline (WITN0912011) .

27. On top of all of that we are being invited to come to meetings with various ministers and officials to discuss the issues and to hear and reflect what is happening, but there is never any change that follows these meetings. We at the Hepatitis C Trust increasingly feel they are tokenistic and appear to be a way to enable the CO and, to some extent, IBCA, to tick the box that says there has been engagement with organisations supporting the community.

28. We had to employ an additional person to assist on the helpline a few months ago, but this is still nowhere near enough. Organisationally, we are overwhelmed. We do not have the resources to manage the number of requests for help we are receiving about the compensation scheme since the publication of the Inquiry's final report and the regulations.

29. The emotional toll on staff and volunteers is massive. We so desperately want to help people as we have always done over the last 21 years, but we simply do not have the capacity and they have nowhere else to go for the kind of support and guidance we provide.

30. Our CEO, senior and helpline staff had a meeting with Sir Robert Francis in October 2024. He advised that once the helpline for IBCA was up and running, we at the Hep C Trust should not receive any further telephone calls. Of course, this did not, and will not, happen – it was clear that they have no understanding of the complexity of people's needs, the level of support they need nor the level of trust that the community have in our service. We were left in this meeting feeling somewhat patronised by IBCA, by which I mean it felt as if we were patted on the back for what we have done holding the fort and told that soon our services would no longer be needed because they would have their own helpline.

31. There is a total misunderstanding by members of the CO and IBCA of the level of mistrust within the community. It is hard to explain how difficult this has been for the Community and for the Hepatitis C Trust on many different levels. If the Hepatitis C Trust did not exist, I do not know where the community, and particularly the whole blood community would go for help.

32. As set out above, we have run regular support group meetings for the community for several years now and despite often challenging or emotional issues coming up they have been a positive space. However, since June last year members of the Community are more prone to tears, needing to offload, clearly frustrated, exhausted and exasperated with it all. They are looking to us for answers, but currently we simply do not have them.

33. One of the things I recently learned was that IBCA had just employed a PR agency at a cost of £250,000. I cannot begin to explain how galling this is - the IBCA can just spend £250,000 on PR when we are scrambling around trying to find enough money to employ a part time member of staff to try to enable us to directly support, inform and help the Community.

34. There is no sense in what steps the CO and IBCA are taking. It simply seems that no one in either organisation is really trying to understand how what they are doing, or not doing, is impacting on the community. How the secretness and lack of transparency is serving only to reignite all of the mistrust that members of the Community have felt towards the government, blood support schemes, medical professionals and other professional bodies for so many years.

35. The way that the CO is acting is very disingenuous. There is no proper engagement. Last year there were 2 (additional) “support” group meetings initiated with representatives from IBCA attending which were a positive step. Individuals were able to ask questions in a confidential and supported setting with us facilitating. They were friendly informal meetings, appreciated by the community but it was soon clear that IBCA are hamstrung. Staff from IBCA were willing and able to listen, and seemed

touched and engaged by the experiences that were shared, but still could not answer attendees' questions in a meaningful or useful way because they simply do not have the power.

36. Therefore, it soon began to feel to the Community that this was just another tick box exercise that said "we have engaged with the community" but with little substance or clarity. Some in the group found it offensive and frustrating. We at the Hepatitis C Trust and the community expected much more active and wide-ranging involvement based on the recommendations in Sir Brian's second interim report and final report from both the IBCA and CO.

37. We at the Hepatitis C Trust and the Community have tried to obtain information from the CO, but we have not been provided with answers. Members of the Community have now been forced to draft FOI requests which are reasonable requests, but the CO is delaying dealing with the request. We have seen these FOIs; they are genuine, simple questions that should not be difficult or take much time to respond to. They are asking about the lack of transparency regarding the expert group that provided evidence on developing the scheme.

38. One of the main issues that is most distressing for the Community, and for which we cannot provide an answer is why there is such a large discrepancy between the way people with HIV and people with HCV are treated in terms of compensation. We are trying to understand where the discrepancy lies to enable us to work out whether there is a reasonable comparison. This difference in payments and the banding appears to have come about from the Expert Group, which operated behind closed doors – initially without even the names of members being public. It did not involve the community, and the discussions of this group have never been made public, so there's nothing on record that explains the discrepancies. The community simply do not understand why the CO did not use the experts that had given evidence to the inquiry.

39. The experts employed to provide evidence to IBCA and the CO had no expertise with the infected blood community, which is why they completely overlooked or forgot any reference to the SCM. As a direct result, the categories now do not align and there is a whole new tranche of evidence that will be required when applying via the Supplementary Route, to which the regulations have not, as of yet, been published.

40. The amount of time and money spent on the "secret" expert group could have been put into compensating individuals. There is no good reason that the CO and IBCA did not use those experts that have provided evidence to the Inquiry. Again, it just shows a lack of transparency and disrespect for the Community, which goes against all Sir Brian said both orally and in his final report.

41. There are serious concerns that the treatment of HCV mono-infected , are unfair and discriminatory under the Scheme. The fact there is such narrow banding of HCV mono infection – especially with the absence of banding for HIV mono infection – is unexplainable to the Community, as is the lower rates of financial loss because HCV treatment has thankfully improved so much over recent years, but so many people had already had to suffer sometimes multiple rounds of interferon based treatments, and not always with a successful outcome. HIV treatment has completely transformed too, but that is not factored in at all. People in the Community don't understand this – they feel there is no reason for such a difference and that it's just about saving money. Also the difference in the payments, in particular the categories of Injury Impact and Autonomy, are so low for many infected with mono HCV infection, these seem to the Community to be unfair and discriminatory.

42. We, and the Community, cannot understand why the Terms of Reference for the Expert Group Report did not include taking evidence from members of the Community, or at the very least giving due consideration to the wealth of evidence gathered by the Inquiry. This resulted in the Expert Group reaching conclusions which are, in many respects, at odds with the evidence before the Inquiry from those with direct experience of living with

the effects of infected blood. This is an issue people ask about, they ask why the scheme has been set up like this, why the infections are not treated as equally damaging, but we cannot provide the answers because we do not understand this ourselves at the Hep C Trust.

43. The IBCA staff do engage more than the CO, but their hands seem tied. They are now trying to engage, albeit too late, and simply appear impotent, as they cannot provide any answers and say they cannot make any changes. That is of no use to the Community. What is the point of speaking with the Community if, as an organisation such as IBCA, you have no power to make any changes. The CO is simply deflecting to IBCA.

44. In addition, we are also receiving telephone calls from individuals infected with Hepatitis B. We have telephone calls from as far away as Canada and the US. Individuals with Hepatitis B understandably, are still very angry. For years they have had no recognition from the government and yet even after the inquiry's final report they are still waiting and still suffering with the long term physical and mental impacts of their infection, the treatments for it and more.

45. I cannot begin to convey the depth of feelings within the Community at the moment. They had fought so hard to obtain a public inquiry and when the final report was delivered, there was such a huge sense of relief due to the fact that they had been so strongly and publicly acknowledged and heard. Their experiences and all the evidence they had been trying to make the government hear for so many years was finally conceded, and a long but overdue apology was given.

46. But then there was the government announcement of the election and concern about its possible impact on the compensation process and members of the community, and many organisations, were thrown again into the pits of despair. Now as a result of the differences in the regulations relating to the compensation scheme, the Community is once again divided. During the course of the infected blood inquiry, we saw the community becoming united, but that has now all been undone.

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

47. None.

48. The Community is faced with large, dense documents that are incomprehensible to most and were directed to our helpline for guidance. This created an unprecedented influx of calls that would have been completely unmanageable but for other Hep C Trust staff and volunteers assisting, as we have received no funding to date, nor have we since the start of the Infected Blood Inquiry

49. There was an initial meeting with the Hepatitis C Trust and Sir Robert Francis and David Foley in late October 2024 (see above 29) – Although we appreciated the opportunity to engage, it was not overly useful and they did not seem to comprehend the depth of work in the helpline service we provide.

50. None of the documents the Government has published on compensation were shown to us in advance, which meant that we had to try to translate the documents whilst trying to field hundreds of calls. No one thought to explain to the organisations trying to support people. In a nutshell, we have received NO external support or assistance to help us to deal with this unprecedented demand on our time. In fact, I would go so far as to say that external organisations, such as CO, IBCA and EIBSS have been directing individuals to us for help, which we welcome, but was also incredibly difficult as we simply cannot keep up with the demand.

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 Hepatitis C Trust have experienced it.

51. Despite everything that was set out in the Inquiry's final report, there has been an abject failure to involve properly and meaningfully members of the Community in the decision-making regarding compensation. IBCA have attempted to engage directly with the Community, whereas the Cabinet

Office – which is where all of the decisions are made, the level of engagement has been practically zero. I do not know of a single instance where the CO has tried to engage community members; organisations and campaign groups yes on some occasions, but not the wider community. IBCA has no power to make changes, which means that, even though members of IBCA have met with the Community, there has been no real or effective engagement with them, or with us as an organisation who could really help, meaningfully, with improving this process.

52. IBCA advertised "community engagement" roles – none of the 3 people selected had an infected blood transfusion and yet transfusions were by far the most common source of infection. There is now a huge amount of pressure on these three people and real upset in the community for how this was done and that it is not fully representative or balanced.

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

53. The Community has not been called upon by the Government to feed into the process for compensation. The Community has not been involved **in** the decision-making regarding compensation. This has meant:

    1. the lived experience of infected and affected people has not been properly or adequately considered.
    2. information and decision making has been really poor
    3. There is now a total lack of trust from the community, which exacerbates the already high existing levels of mistrust

54. The most important point is that the tariff-based model was decided upon for expediency, because this needs to happen quickly. However, a tariff-based model is not suitable for all. For people who need immediate redress, the core route provided an efficient way to get compensation paid swiftly. However, others in the community need an element of individualised assessment.

55. There are no two cases of claimants who are identical in this process. The Government has chosen to set the restrictive tariffs but the IBCA **MUST** be given discretion and flexibility with awards based on individuals evidenced losses, otherwise the entire notion of an independent compensation authority is questionable. There must be a mechanism for individual claimants to come to the IBCA and request a more bespoke assessment based on actual loss suffered and based on an array of evidence where the tariff is insufficient. All heads of loss should be open to be considered and claimants given the option of individual assessments, as is being provided through the post office compensation scheme.

56. That recovery of quantifiable losses would be recoverable under any standard personal injury compensation claim so the compensation scheme should not be more onerous or restrictive. Also the evidential requirements should be lowered significantly based on the number of years of denial which has compounded the injustice and this should therefore not discriminate and disadvantage the claimant

57. This is from the Government's website on PO claim assessment:

Assessment of claims

Q. How will my claim be assessed?

A. DBT will assess all claims in the first instance. Claims facilitators will be appointed to resolve any disagreements between you and DBT. Should both parties not agree on any element of the claim, it may be referred for review by an Independent Panel.

Your claim will be assessed using the information available, with considerations of fairness and applying the relevant legal principles outlined in the Scheme Guidance and Principles.

The assessment will very much depend on the individual circumstances of each application, and the information and evidence supporting it.

58. I cannot see how an assessment can depend on individual circumstances when there is no discretion within the IBCA to respond to individual circumstances.

59. If the community had been properly consulted this might have meant that the mono HCV compensation payments would not have been broken down to the nth degree with no consideration of the impact of the disease and the SCM would not have been an afterthought.

Please describe the impact upon you and your colleagues The Hepatitis C Trust of the matters set out in 1-4 above.

60. In a nutshell, as a direct result of the government and CO failures, we, as an organisation:

- are overrun as a service
- do not have time to support people properly
- because we are so stretched, and because so much complex information is being released, we do not have time to fully engage with the compensation process, and therefore cannot provide sufficient information to, or provide sufficient representation for, the community. We find it impossible to digest and process the information coming out of Government and get to a point where we can translate this to the community in good time – this is really problematic for staff and for callers
- have had to bring in people from other parts of the organisation who have limited specialist infected blood knowledge
- find it massively draining and debilitating for our team – everyone is completely exhausted, and the team has done hours of overtime
- have incurred additional costs – cover staff, new staff, additional clinical supervision, volunteer expenses

61. We remain totally unfunded which has put considerable pressure on the rest of the Trust's work to enable us to continue to provide this absolutely vital service (there is no other specific "helpline" providing this service, and nothing at all that provides for the specific and very sensitive needs of the whole blood community).

62. The impact of the volume of calls and emails on the Hepatitis C Trust Information and Support Service has been relentless and overwhelming, since the launch of the Inquiry report in May. Following the announcement of the compensation scheme last Summer, enquiries more than doubled from the previous year; 8700 in total in 2024, 7099 of which were in the period May – to December 2024. In addition, in January 2025 we took 752 calls and emails.

63. Since the Inquiry report was published in May, our helpline staff should have worked just over 600 hours in total. And yet they took 1,156 hours of calls in that period. Effectively, our team has been working double their hours, every single day, for eight months. And in addition, they have other work and responsibilities to carry out on top of taking telephone calls and responding to emails.

64. In addition, we have had to increase the provision of online groups in the evenings and webinars to bring the community together and keep them informed, supported and to ensure individuals do not feel isolated.

65. Staff and volunteers on the helpline have fortunately had the passion and commitment to continually do all they could to provide this support and information to the infected blood community, but the greatly increased hours has impacted on them all. Without that personal dedication to the community and willingness to go the extra mile, the service may have collapsed months ago.

66. The volume of angry, confused and distressed callers – many of whom reveal extremely traumatic experiences connected with their infection(s) and or other events in the course of their calls and emails, has resulted in staff having to have increased clinical supervision to deal with the stress and emotional fallout.

67. It is difficult for staff/volunteers to keep abreast/digest the ongoing influx of often complex information and maintain a quick and responsive service for the community, which meant for a time, for the first time in over 20 years,

our response sometimes came much later than immediately/or within 24 hours that we delivered previously.

68. Many other staff at the Hep C Trust have had to be engaged, on many occasions since the Inquiry reported and the compensation process started, to assist with manning the phones, taking them away from other work. The volume of work on the helpline and associated campaigning, attendance at groups, external meetings, webinars, working groups, media etc has resulted in senior and other staff having to get increasingly involved, limiting the time they can spend on other aspects of their role.

69. In addition, speaking to callers who are end of life/deeply traumatised and physically ill or compromised, supporting them the best we can with the knowledge that resolution did not/may not come soon enough is highly distressing and frustrating. Even whilst writing this, a message came in that a long term caller we have supported over 19 years has passed away from liver cancer.

70. For me and the other members of staff and volunteers at the Hepatitis C Trust who have been working on this, the impact has been indescribable. It has been completely overwhelming. Personally speaking, and despite managing the helpline for 21 years and being acclimatised to hearing extremely difficult stories, it has been very destabilising. Though I have worked with individuals and their loved ones through testing, diagnosis to end of life, often over months, years and in some cases decades, getting to know them often very personally, meeting them at the Inquiry or in other settings and trying to support and guide them in the right direction and assist them however we can.

71. I have always been able to cope and manage. Even from the beginning of the Infected Blood Inquiry process when demand rapidly increased and we were receiving year on year increases in our call levels I felt able to cope.

72. However, the sheer number of telephone calls since May 2024 to date, means the situation is completely unprecedented. It is increasingly difficult

to manage this in a general sense and has had a huge personal impact on me. Having worked in this role so long I remain 100% committed to the community I serve, but the impact on my quality of life has been incredibly difficult as I have thought or done little else than work continuously through this time, which has had a negative impact on my own physical and mental health.

73. I have little or no time to absorb the torrents of information coming in, and when I do, I am usually commuting to, or from work, or at home at the weekends. It is all consuming. However, the reason I keep going is because I care deeply about all our callers having got to know them, meeting many of them through the Inquiry, our groups and understanding their highly individual and personal situations very well – and I am acutely aware that there is simply nowhere else for them to go where they can get the level of support we can provide.

74. I am aware that during the COVID inquiry there has been reference to healthcare staff suffering moral injury because due to lack of resources, they have been put in a position where they have not been able to provide the best treatment and care they could for their patients. This caused them a moral injury. For me and the other staff and volunteers at the Hep C Trust, it is the same. I cannot begin to describe the personal distress and emotional turmoil we feel because of feeling very concerned that we may be unable to continue to provide the consistent, kind, thorough and patient level of support to this Community in the way we have for the last 21 years and in the way we want to continue to do. There is no doubt in my mind from the feedback we get, that this service is highly valued by the community and they not only want, but need, it to continue.

75. The reason why I feel this way is as a direct result of the impact on the way in which the CO has gone about trying to set up a compensation scheme. A process that has lacked transparency, that has lacked meaningful engagement with members of the Community and organisations such as the Hepatitis C Trust, Haemophilia Society and campaigners/campaign groups. It is a process that has ignored all of the very clear

recommendations in Sir Brian Langstaff's report and become a process that has resulted in unfair and discriminatory tariffs…and all of this at what cost to the public purse? And with a process that is yet to even start but has already caused so much distress.

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.

76. In a nutshell the impact on the Community as a direct result of this process can be set out as follows:

- prolonging the trauma everyone is facing;
- pitting people against each other, and nobody can explain the reasoning behind the decisions that have been made;
- making people feel alienated, upset, angry by the process. When individuals call us they are angry, highly stressed, confused and tearful;
- people are losing faith in this system before it has even started. There is confusion around the scheme and no explanation why the tariffs are set as they are, particularly in relation to HCV;
- people are already anticipating difficulties now about what might happen their claim finally goes ahead.

77. The impact on the community has been absolutely devastating, it has caused upset, confusion, anxiety, fear, desperation and division unlike anything we have experienced so far in the 21 years of supporting them.

78. Not only do we hear on the calls, but we can see in our support groups and other face to face engagements with the community, how weary, angry and understandably cynical individuals are feeling. No one has expressed confidence or satisfaction in any part of IBCA despite their more recent willingness to engage.

79. There are so many outstanding and unanswered questions that were asked of IBCA in our meetings, informal groups and webinar. Any responses we have received revealed little or nothing new which was incredibly disappointing.

80. Despite IBCA "engaging" more directly with the community recently, people feel fobbed off yet again; questions are not answered clearly or they are batted back to the CO who are not being transparent and open. This is creating upset and trauma incomprehensible to most.

81. Below is an excerpt from the Inquiry's final report:

> "although now accepting that wrongs were done, the Government does not yet appear to be clear as to what lessons it has already learned, or seeks to learn, from the history it now accepts."

82. With compensation and the lack of meaningful engagement from the Government/CO what has actually been learnt from the Inquiry? Where is the candour and transparency? The government have learnt very little despite a seven-year inquiry which cost taxpayers millions.

83. Regarding the IBCA Facebook page, although a channel of communication, it will not be accessed by many and as it is public. Potential claimants are revealing their names and personal information on the site, which means that they have the possibility of being targeted and scammed. And for what? As no responses to queries have been posted on the site, nor warnings not to share personal information there.

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

The Hepatitis C Trust

84. Funding immediately to increase our ability for capacity and reach, specialist knowledge. Funding to enable us to provide an advocacy service.

85. In addition, we at the Hep C Trust require training. We must be being thoroughly taken through the process of compensation with all the different groups/routes by IBCA so we can fully the understand that process ourselves to enable us to provide better support our callers, who we have

no doubt, will continue to speak to us throughout the initiation and process of their claims.

The Infected/Affected communities

86. The government/CO must start being open, honest and transparent. The government/CO must start to have transparent and meaningful engagement with the community. The scheme must ensure that Individualised assessment when requested ensures proper and fair justice to all. The government/CO must provide a clear timeline to enable individuals to plan. There must be guidance on what, if anything, individuals need to do in the meantime.

87. The government/CO must urgently address the disparity between HIV infected and HCV (or B) infected – there is a gulf between payments that does not reflect the severity of an HCV infection – whether physical in terms of liver disease and overall increased risk for liver cancer, or the myriad other serious conditions, complications and life changing impacts that people with HCV can develop or worsen over many years. In addition, the older interferon based treatments must be taken into account when calculating compensation levels.

88. The government/CO must ensure claimants (and particularly whole blood infected/affected as they have nowhere else to go) are signposted to us for additional support to ensure ALL their concerns or questions are addressed. We can also support and guide them in so many other ways, preparing mentally or practically, linking them to IBPS etc for psychological support to help them to move on and "draw a line" under their experiences when the IBCA process is finally over. But we must be given the additional resources we require, as set out above, to provide this support.

89. Individuals must be provided with a compensation calculator for everyone to use to have an informed idea of what they are likely to expect. There must be more clarity on how the "balance of probabilities" will be used when individuals have already done all they can to gather evidence they can and there simply is nothing "new" or persuasive they can bring to the table. And

how will this be different to the "balance of probabilities" criteria used by EIBSS?

90. The Community wants a clear explanation about how 250+ people have been chosen at "random" and want information to spell out exactly what groups they have been drawn from for early claim offers. In addition, many report that despite registering to be part of consultation/surveys etc with IBCA, they have not been contacted – why? How were the 250+ selected? The Community is entitled to know the answers to these questions.

91. For those that get claims acted on swiftly and settled, interest gained on their investments may add to it considerably, compared to others who may have to wait months, or possibly years to have their claim settled – how can this issue be fairly resolved? An explanation must be provided.

92. People's lives are on hold whilst this process continues. For individuals who want/or need to move home, settle debts, get their affairs in order, enjoy the limited time they may have left (given that the majority are in any event an older population) they cannot. They feel "stuck" because of the failures of the government/CO to sort out an easy to use, fair and transparent compensation scheme.

93. One person we have supported over the last few years who falls in the post 1991 group explained they were living on soup, in order to provide more food for their children. They would greatly benefit from the psychological support available but cannot access that either as not on the IBSS. They are under the care of doctors for their mental health but the drugs they are prescribed to help stabilise this they don't always take as they cause fatigue, affecting their already limited ability to work. They and others in the post 1991 group cannot understand why, if it's now acknowledged as pre-1996, that they can't access the blood support schemes now, which would go some way to relieve the immediate financial and other stress they face from not being included.

94. For all of the reasons above, we make a desperate plea to the government/CO and IBCA to resolve this situation so that individuals can obtain the compensation they should have received so long ago. We urge the government to take action now to stop compounding the hurt, anguish, distress and hardship that have faced this community for decades.

Statement of Truth

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

Signed GRO-C ______________________________

Dated February 2025________________________