Witness Name: Katherine Victoria Burt
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INFECTED BLOOD INQUIRY

FIFTH WRITTEN STATEMENT OF KATHERINE VICTORIA BURT ON BEHALF OF THE HAEMOPHILIA SOCIETY UK

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

I, Katherine Victoria Burt, will say as follows:

Section 1: Introduction

1. My name is Katherine Victoria Burt, and I am known as Kate. I am the current Chief Executive of the Haemophilia Society ("the Society"). I have held the position of Chief Executive of the Society since 5 October 2020. All references hereafter to "the Society" are to the Haemophilia Society unless otherwise indicated. I am authorised by the Society to make this statement. This is the fifth statement that I have provided to the Inquiry.

2. In order to fully respond to the Inquiry's Rule 9 request dated 14 January 2025, I have sought input from the former Chair and current President of the Society,

Clive Smith, the current Chair of the Society, Conan McIlwrath and the Society's Head of Public Affairs and Policy, Debra Morgan.

Section 2: Inquiry questions

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

3. Less than 24 hours after the publication of the Inquiry's Report in May 2024 the Paymaster General made the announcement as to the details of the Infected Blood Compensation Authority ("IBCA") and the payment levels. It was incorrectly reported that everybody would be receiving in excess of £1m.

4. Given the proximity of the announcement of the compensation scheme to the publication of the Inquiry's final report the Society did not (nor did the wider infected and affected community) have the opportunity to fully digest the Inquiry's findings before having to deal with the immeasurable amount of additional work created by what felt like a rushed announcement by the Government in respect of compensation. On 7 May 2024, the Society met with the then Paymaster General, John Glen MP, where Clive Smith and I suggested that the government should not make an announcement in respect of compensation until the community had had the opportunity to digest the Inquiry report as we did not want any compensation announcement to overshadow the report's findings. Unfortunately, this concern was ignored.

5. Since the announcement, the Society simply has not stopped; if anything the Society has been under more pressure than at any point since the Infected Blood Inquiry was announced in 2017. By way of illustration, in May 2020 the Society received 134 calls, in May 2022 it received 186 calls in May 2024 it received 641. During the third week of May 2024 alone, the Society received 448 calls. The e-mail traffic has also increased significantly, but we do not have the analysis available to evidence the true volumes at this stage. This is not sustainable for such a small charity.

6. The Chair of the Society at the time, Clive Smith, attended the Paymaster General's announcement in the House of Commons and has been interviewed numerous times by the media about the details of the scheme since that date. Likewise, the Society's current Chair, Conan McIlwrath, has also been interviewed multiple times by journalists whose interests quickly turned from the Inquiry report to the compensation announcement. As described by Conan "*Something that was supposed to be our community's moment of truth and justice was immediately hijacked by a rushed political move*".

7. Since the announcement, Conan has attended numerous meetings with MPs and Peers in an attempt to have some input into the initial compensation regulations laid by the previous government and into the future regulations set to be laid in March under the current government. Whilst MPs and Peers have been supportive no meaningful changes have been made.

8. As stated above, the Society has been completely overrun with queries since the announcement of the compensation scheme. The queries vary considerably in their complexity ranging from how to register to apply to detailed questions about eligibility and tariffs. Each enquiry is unique and time consuming, always necessitating patience and compassion as well as an in depth understanding of the compensation scheme which our staff have built up themselves. Attached at Exhibit WITN6392289 are two example e-mails showing the complexity of some of the queries received.

9. In order to assist with the establishment of the IBCA the Society:

   a. Surveyed its members in June 2024 to feed into Sir Robert Francis's work. 872 people replied to the survey which is a record number of respondents for the Society. This reflects the strength of feeling about compensation amongst the Society's members.
   b. Made a submission on the proposed Infected Blood Compensation Scheme in June 2024 (see WITN6392290), summarising the issues, concerns and anomalies arising from the scheme documentation at that stage.

c. Arranged webinars to inform our membership as best we could about next steps with the compensation scheme. We held a webinar on 29 May 2024 which had been designed to discuss the inquiry's findings, but was completely diverted to the subject of compensation due to huge uncertainties about the scheme at the time. A further compensation specific webinar was held on 3 September 2024 (see Exhibit WITN6392291) and a Probate and Wills webinar on 6 November 2024 (see Exhibit WITN6392292). Over 300 people attended each webinar. Before May 2024, less than 100 people attended individual seminars held by the Society. As a result of the increased attendance, a more expensive Zoom licence has had to be purchased, placing further financial pressure on the Society.

d. Attended IBCA meeting to meet non-executive directors where Clive, Conan, Debra and campaigner Andrew Evans presented. Clive spoke about the history of the scandal and how the Inquiry was finally achieved and spoke to the Society's involvement in the Inquiry and the way in which we supported our members through the process. Debra's presentation focussed on the stress and anxiety the community had endured and how IBCA needed to understand the community and to be patient and empathetic to all. Debra also talked about the fact that not all individuals would have complete documents to support their claims which would require the scheme to consider the probability of infection as opposed to definite evidence of infection. Debra also implored IBCA to learn from the mistakes of the past, particularly surrounding trusts and schemes in order to earn the trust of the community. Conan spoke about looking forward and working together as a trusted partnership and critical friend in the hope of having a transparent and mutually respectful relationship. A copy of the slides can be found at Exhibit WITN6392291.

e. Arranged the 'Big Get Together' conference for Society members which included a session attended by David Foley, interim Chief Executive of IBCA. The Society asked for questions in advance of the session to assist Mr Foley in his preparation for the conference which resulted in the need for further co-ordination and work associated with moderating the session.

f. Held a webinar on 9 January 2025 with IBCA. The Society again co-ordinated all of the questions from our members in advance. We received a significant spike in e-mails and calls to the Society's office both before and after the event. This is further proof of our community's increasingly urgent need for answers and clarity.

g. Sent numerous e-mails and attended various meetings and calls with IBIEPS, EIBSS, IBCA, Cabinet Office, Probate Service and HMRC regarding tax on interim estates and inheritance tax forms.

h. Trustees have spent considerable time with the UKHCDO and NHD to consider how IBCA could use the data available through their systems.

i. Posted information on the Society's website and social media which, unfortunately, has also led to an increased need to moderate comments and users. The tone of some of the comments reflects the frustration felt by the community.

j. Experienced a significant increase in the level of phone calls into the general office. The individuals who contact the Society demonstrate a range of emotions including anxiety, anger, distress, confusion and frustration. Many calls are emotional, with people feeling powerless to move on from their past or simply overwhelmed by the complex bureaucracy they are facing.

10. In the 2019 – 2024 parliament the Society provided the secretariat to the All-Party Group on Haemophilia and Contaminated Blood ("APPG"). After the 2024 election the Society worked with Clive Efford MP to reform the APPG. The APPG is a group of around 50 MPs and Peers with an interest in bleeding disorders and the contaminated blood scandal. It meets irregularly for members to discuss issues related to compensation, the wider Inquiry recommendations and standards of care and treatment for people with bleeding disorders. In our role as secretariat, we maintain the mailing list and webpage for the APPG, ensure the APPG meets its formal parliamentary requirements, organises meetings, produces minutes and writes briefings and updates for the members.

11. The APPG had its most recent AGM on 22 May 2024 but the group ceased to exist shortly afterwards with the dissolution of parliament on 30 May 2024. In

Summer 2024, Clive Efford MP agreed to be the Labour Co-Chair of the APPG. The Society briefed the group in advance of the general debate in the House of Commons on 19 November 2024 and the anniversary of the government defeat on the Victims and Prisoners Bill on 4 December 2024. Attached at Exhibit WITN6392294 are examples of the ways in which we support the work of the APPG.

12. Each year, a Service of Thanksgiving and Remembrance is held at St Botolph Without Bishopsgate in the city of London. The service was set up 30 years ago by a former chair of the Haemophilia Society to support people whose loved ones with a bleeding disorder died as a result of treatment with contaminated blood products. The event in October 2024 was the highest attended service for a number of years with 180 attendees. Many attendees came with children and grandchildren, illustrating the on-going generational impact this scandal is having on the bleeding disorders community.

13. In addition to the work of the Society as a whole, individual trustees and staff members are being contacted directly by concerned members of the infected and affected community. One individual described the pressure as “intolerable” and considered closing their social media accounts as a result of the relentless messages seeking support and reassurance. This is a burden which should not fall on the shoulders of individuals, however, this is an inevitable consequence of the lack of centralised support for applicants– see further below.

14. It should also be borne in mind that the Society’s staff and trustees are not all based in London, resulting in significant travel to attend the various meetings.

15. The Chair has also:

    a. liaised extensively with the Irish Haemophilia Society, Haemophilia Northern Ireland, Haemophilia Scotland and Haemophilia Wales along with other campaign groups to seek to collectively work through the various campaign routes for support;
    b. attended the re-founded Haemophilia and Bleeding Disorders Alliance (“HBDA”) which consists of the Society, Haemophilia Scotland,

Haemophilia Wales, Haemophilia Northern Ireland, the haemophilia centre directors organisation known as the UKHCDO, the Haemophilia Nurses Association (HNA) and the Haemophilia Chartered Physiotherapists Association (HCPA). The HBDA was re-founded after the publication of the Inquiry's final report to support the implementation of its recommendations to include compensation;

c. attended and spoke at the IBCA Non-Executive Director training day which resulted in a conversation with the Director of Digital at IBCA with whom the Chair has had multiple meetings since in order to attempt to assist IBCA with questions around data and systems;
d. helped to facilitate an IBCA town hall meeting in Northern Ireland;
e. met with the Paymaster General;
f. attended two meetings with the Irish Society; one in Dublin and one virtually;
g. met IBCA with the UKHCDO as a patient representative.

16. It is important to note that all of the above has had to be undertaken in addition to Conan's 'day job'. The relentless pressure of spearheading compensation-related work detracts from his ability to focus on other aspects of the Society's work. The Society is now in considerable financial difficulty, mainly as a result of the diversion of resources as detailed further below.

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

17. Unfortunately, there has been no external support or assistance available to the Society as a whole or individual trustees and members of staff in undertaking the work as outlined above. Whilst the Inquiry is maintaining the services of the Red Cross there has been no support available for colleagues and other campaign groups.

18. The Society has supported and invested a lot of staff time into supporting the setting up of a psychological support system NHS England. I have personally attended 17 hours of meetings either with the Stakeholder or Expert Advisory

Group Psychological Support group, in addition to a further four hours with the NHS England team. Likewise Debra Morgan has spent 21 hours attending similar meetings. The Society acknowledges that a lot of work has been put into this project with the desire to get things right, however the slow progress means that there is still very little bespoke support for the infected blood community in England.

19. The Society has been lobbying for specialist psychological support for the UK's infected and affected community since it wrote to then Prime Minister, Theresa May, in September 2018 and the Cabinet Officer Minister, David Lidington in January 2019 (see Exhibit WITN6392295) amongst others. The Society also highlighted its concerns by initiating media coverage on Channel 5 News on 24 February 2020, to coincide with the issue being discussed at the Infected Blood Inquiry. Happily, services in Wales, Northern Ireland and Scotland have improved dramatically since then, but the same cannot be said for England. We were informed by the Paymaster General in August 2024 that the Infected Blood Psychological Service was to be ready to support its first patients in England later in the summer of 2024 – see letter from Paymaster General to the Society dated 13 August 2024 at Exhibit WITN6392296. As I write this, the Infected Blood Psychological Service is still not fully set up with only a few psychologists in place and the national structure and referral system still not operating.

20. This lack of external support has put considerable additional pressure on the Society. The infected and affected are clearly struggling and have nowhere to turn for support therefore they call the Society. The Society staff are providing emotional support as well as what guidance we can on complex financial and, in the case of probate issues, legal matters. Some callers are extremely isolated and have not confided in friends or even family about their link to the contaminated blood scandal. They know their call will always be welcome at the Society, but there is a limit to the support and information we can offer them. A number of people phone us every week with the question: 'Has anything changed?'.

21. Financially, the Society has received no support whatsoever. With our main fundraiser, Debra Morgan, largely diverted onto compensation-related duties, it has been extremely challenging to raise the funds needed to maintain the charity's core services. We are operating in a very difficult financial landscape, with ever decreasing funding sources. To ensure we are still here to support the next generation of people with a bleeding disorder as well as meet the demands of our members today, we urgently need the assistance of government funding.

22. The Society has become ever more reliant on the goodwill of volunteers and professionals willing to assist on a pro bono basis.

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 the Haemophilia Society have experienced it.

23. As far as the Society is aware, infected and affected individuals had no involvement in the decision making on the initial set up of the scheme or IBCA. These decisions were all made by the Paymaster General and the expert group, and simply communicated to the community in May 2024.

24. Sir Robert Francis conducted a consultation in June 2024 and that was the first and only opportunity the Society was given to feed into the primary regulations. Since then, there has been limited engagement as to the secondary recommendations.

25. The APPG working alongside the campaign groups (to include the Society) and the support of the Inquiry resulted in an amendment to one element of the compensation scheme; this means that adult siblings are now included as being able to claim compensation.

26. The Society has been asked for support by IBCA. During a meeting on 23 October 2024, one of the Non-Executive Directors at IBCA suggested that the Society should be considered a consultant for IBCA and reimbursed for the time

incurred as our experience and input was so invaluable. This has not happened. The Society feels it has a responsibility to its members to engage with IBCA however there is a feeling that its time and expertise is being taken for granted.

27. We have attended various meetings with the Paymaster General and the Cabinet Office. At one meeting, representatives of each group in attendance was given four minutes to make submissions. The length of time allocated was consistent across all attendees, regardless of how many people they represented. For example, one person may have been there in their personal capacity and they were given four minutes, the Society representative who attended, attended representing all 5,000 members of the Society, but they were also only afforded the same time to make submissions. The meeting with the Paymaster General on 11 December 2024 was highly choreographed, which felt more like an obligation to engage rather than actively listening to the needs of the community. The meeting did not offer the chance of meaningful engagement, which the Society had requested. Being given four minutes to summarise the positions is not enough time to adequately reflect the range of needs and concerns voiced to us by our members.

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

28. The Society's principal concern is that the infected and affected were not involved in any of the decision-making regarding compensation until the majority of the key decisions had already been taken. There were some engagement meetings held with Sir Robert in June 2024, but this was long after a significant number of key decisions had already been made. Many of the community feel the lack of transparency and lack of community engagement of the expert group prior to Sir Robert's engagement sessions has caused many of the ongoing issues.

29. Many decisions about the compensation scheme were shaped by the government's Infected Blood Inquiry Response Expert Panel which did not consult with the infected blood community at all in making its recommendations.

30. The most important decisions on compensation relate to the core route tariffs and to the eligibility for those tariffs. These decisions were taken by the Cabinet Office alone based on the advice of the expert group. Despite repeated approaches by the Society and by MPs on behalf of the Society, we have been repeatedly told that they will not revisit those decisions. During a debate in the House of Commons on 19 November 2024, Clive Efford MP stated "The Cabinet Office controls the decisions of the Infected Blood Compensation Authority. I hear what the Paymaster General and Minister for the Cabinet Office said to me earlier about operational independence, but ultimately the Cabinet Office is making the decisions and victims are not included in the way that Sir Brian recommended. Victims feel that decisions are being made without their involvement. Those suffering with hepatitis C feel particularly excluded and do not feel that their suffering has been fully recognised in the compensation scheme" (RLIT0002475).

31. Since November 2024, the Society has received distressed calls and e-mails from bereaved relatives unable to navigate the interim compensation payment to estates. This payment is administered by the infected blood support schemes in Wales, Northern Ireland and Scotland and by the Infected Blood Interim Estates Payment Service ("IBIEPS") in England. Some claimants had been given a confirmed payment date and submitted their bank details, only to be told days later that there was a problem with their claim and more documentary evidence was required. These claimants were re-traumatised and confused by the conflicting information they received. The Society escalated these issues directly with senior Cabinet Office officials and some solutions were found but the Society is continuing to receive calls which require further intervention and clarification.

32. For example, the Society has been contacted by an individual who was told that her claim was successful on 13 January 2025 and was asked to provide her

bank details, which she did. Then on 22 January 2025 she was told that her claim would not be processed on the basis that she had only demonstrated a ‘line’ of succession and not a ‘chain’. There was no explanation within the correspondence as to what this meant or what she needed to do to enable her to submit a successful claim. The Society made contact with the Cabinet Office who subsequently looked into the matter and provided some further guidance on 30 January 2025. This is just one example of the complex queries being raised of the Society and the ways in which it is attempting to assist its members.

33. Significant changes in the interim compensation (estates) process have been made as a result of the Society’s questioning and persistence in trying to resolve some difficult cases. For example, the Cabinet Office has issued at least two fact sheets to support scheme staff to provide guidance on issues the Society has raised.

34. Had there been engagement with the Society and other campaign groups during the set up phase of the scheme, the situations like the above could have been avoided. The Society and others would have been well placed to flag potential issues when scenario planning. A decision could then have been made at an early stage as to what should happen. Instead, mistakes and oversights have been dealt with ‘on the hoof’ with clumsy Cabinet Office interventions and poor communication from IBIEPS. These errors have caused, and continue to cause, great damage to bereaved families.

Please describe the impact upon you and your colleagues within the Haemophilia Society of the matters set out in 1 – 4 above.

35. It is difficult to put into words the impact on my colleagues of the matters set out in 1 to 4 above. We were all so full of hope following the publication of the Inquiry’s report but that feeling was short lived as soon as the announcement regarding compensation was made less than 24 hours later.

36. Due to the complexities and sensitivities around these issues, most infected blood related enquiries fall to three members of staff, all of whom work part-time hours. It is not unusual for calls to last longer than 30 minutes, as people want to talk about what happened to them with people they know will understand. While everyone is happy to spend as much time as needed on an enquiry, this inevitably has a huge knock-on effect on the other parts of their roles. These roles include policy, communications and fundraising, all crucial cogs in maintaining and improving our day-to-day support work.

37. Trustees and staff have spent a considerable amount of time attending meetings and liaising with the various departments, groups, establishments and committees. This is all voluntary and incorporated around their own professional careers, relationships and personal commitments. Each individual has changed their plans at short notice to do what they can to support the ongoing work sometimes to their own personal detriment.

38. The Society lives by its values of compassion, empowerment and resilience. Since 20 May 2024 I have witnessed our trustees and staff team demonstrate all these to an incredible level to support our community. But we have been tested to our limits as individuals and as an organisation. As Chief Executive, it is very difficult to see the impact this has had on my colleagues, both staff and trustees. I am incredibly proud of the support that we are offering our members in such challenging circumstances but worry about its long term cost. I cannot begin to surmise as to how it feels for them, therefore I have quoted below what three individuals have expressed to me in preparing this statement.

39. In the words of Debra Morgan "*The staff members have concerns on the burden placed on our trustees. Over the summer many of them had to take a step back due to the stress this has placed on them. We have to remember that many are affected and are understandably concerned about their own futures and security as but they still give their own time to support individuals as well as continue as volunteers for the Society".*

40. Clive Smith states "*When the Inquiry reported, it was hoped that for the first time in decades we might be able to start looking forward, more than we look*

back. That hope has vanished very quickly meaning that staff, trustees and members' time has been sucked into working on compensation, to the detriment of our wider community.

Compensation was recommended a long time ago. The amendment in Parliament was voted on a year before any compensation offers were made. The delay on the community is intolerable. However, the stress on a small charity has been unbearable at times. Having chaired the Society during the Inquiry, I couldn't have been prouder of the team we gathered to work on the Inquiry, particularly Kate, Debra, Jessica and Jeff. We have done our inadequate best to manage everyone's physical and mental health during this time. As a charity, we cannot afford to pay bonuses, so we have rewarded staff (when possible) with additional time off and unpaid sabbaticals to enable them to keep going. Much of this has been possible because we all felt that there was an end-point. The Inquiry report and compensation announcements would allow us to begin to move on. What we thought was an end, in reality has been the beginning. The beginning of something as all-encompassing as the Inquiry itself. The sparse compensation announcement, followed by a period of political uncertainty due to the general election, followed by a period of bedding in by the new government, followed by the grinding into action of IBCA has left an information vacuum which we and other organisations have had to fill. The government has had no meaningful engagement with the community at all. Meetings have been perfunctory at best and simply opportunities for ministers to claim that they are engaging.

As the former Chair of the Society I am incredibly worried that excellent members of staff will decide to leave our small organisation. The hole that any one of them would leave would be huge. Their experience and knowledge of the Inquiry and our members could never be replaced. They are all truly irreplaceable. But more than that, I worry about the personal impact this is taking on all of them – it keeps me awake at night. Every single one of them goes above and beyond what we could ask or expect of them. The long term consequences on our amazing team should not be underestimated. None of them have been infected, but all of them have been deeply affected by what *they have witnessed and experienced over recent years. Much of this should not have been necessary. They should not have been a proxy for the lack of psychological support, particularly for those in England. They should not have been doing the job of the Cabinet Office in answering questions about compensation since the announcement on 21 May. I have no doubt that they have hidden the true personal cost to themselves from me and others for fear of adding to our own personal situations. This has to stop. Now. The Society needs funding. The staff team need time to breathe. They need time to recover and heal. If it doesn't, I sincerely believe that the organisation will struggle to continue and exist in the very near future."*

41. Likewise the current Chair, Conan McIlwrath has stated "*As a volunteer and a victim, the time spent has been horrendous, especially in many ways when it feels like you are not progressing on multiple fronts. After the Inquiry reported I felt like finally justice had been done and we had the truth, this was unfortunately very short lived and emotionally I am beginning to feel drained. I am not ashamed to admit that over the last few months I have suffered low mood, anger and in many ways a feeling of burnout.*

This was supposed to be an exciting new chapter, I had taken on the role of Chair, I hoped to be able to concentrate in reshaping the Society post Inquiry to concentrate on its charitable and advocacy work which I hoped would be funded and to step away from campaigning; this has not been the case.

I looked forward to having complete financial security for myself, my mother and my son, and still, we face this unknown and stress with lack of answers and timescale of the scheme.

I see many of my colleagues facing the same challenge and honestly worry about the capacity of the staff with the additional workload that this has put on them.

I have only taken over as Chair of the organisation since September and now witness firsthand the pressures that the staff have to deal with. Repeated *requests for information, from the community, IBCA and Government. Harrowing stories of people's hardship told time and time again. Constant pressure from us as a Board of Trustees in relation to financial security, along with all of the "business as usual" operational tasks like, engagement with other organisations (nationally and globally), running events, trying to stay up to date with new treatments, working to ensure we meaningfully represent everyone with a bleeding disorder and managing working groups and subcommittees. I look on with great admiration at how my colleagues are able to juggle all of this, however at some point something has to give. We have already decided to scale back events this year, due to financial and resource constraints. Debra in particular spent over 3 days setting up a webinar for the benefit of IBCA alongside fulfilling her normal duties, burnout and financial collapse is a real risk.*

To reference a post I saw on social media which wholeheartedly resonated with me was 'The Inquiry gave us our truth, but it gave the government control'".

42. I wholeheartedly agree with all that my colleagues say above.

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.

43. As stated above, the impact on those infected and affected has been and continues to be considerable. The lack of preparation and forethought about the issues that may arise means that IBCA and the Government are only learning from their errors after causing further stress to those who have already suffered so significantly.

44. The current position remains one of significant uncertainty. People want to make plans and look to what the future may hold, but the lack of clarity around what compensation they may receive and when it might be paid is exacerbating anxiety about the future. In May 2024, following the vindication of the Inquiry's findings, many believed that they had finally reached the end of their fight for

justice and recognition of their loss. Although a lot has been achieved since that time, it is heartbreaking to see how quickly that euphoria has changed to despair. The impact of the current uncertainty on people's physical and mental health cannot be overstated.

45. As a result of the lack of engagement the community is losing trust and there is in fact an element of mistrust around the true independence of IBCA. The community is concerned around the level of control the government will have over the decisions IBCA will be able to make. As detailed further below, the specificity of the regulations is perceived to be a means in which the government is controlling the decisions to be made which in effect is resulting in IBCA being a version of the Infected Blood Support Schemes. Many feel that this is a way of the government controlling and reducing the levels of compensation. Many of the infected and affected are now actively pursuing litigation as they feel they are not being listened to again.

46. The impact of the lack of a functioning psychological service is tremendous. The Society is receiving phone calls on a daily basis from individuals who simply do not understand what is happening. Some people are phoning every week and are understandably leaning on the Society for support where they can find no other. Many do not even recognise the mental distress they are under.

47. Those given the responsibility to oversee the implementation of compensation are not communicating effectively with any of its participants nor the charities and support groups that are assisting the infected and affected. For example, the Society found out through social media that there was a dedicated probate service for infected blood victims. This was not communicated to the community and the probate service themselves did not tell the Society when it was attempting to understand the process.

48. Attached at Exhibit WITN6392297 are examples of telephone calls that we have received. People have informed us that they are not sleeping and are extremely upset by the whole process.

49. The community has failed to trust the government for decades however, Conan believes that "*Throughout my entire time involved in this, pre, during and post Inquiry, I have never seen the community as stressed, confused and actually scared of what the future holds. The Inquiry gave them an outlet, unfortunately the entire compensation process has reinforced the mistrust in government and establishments that we thought and hoped were behind us".*

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

50. There has to be an acceptance by government and IBCA that they have made mistakes and when that acknowledgment happens, they have to accept that changes are needed. In order for this to happen there needs to be meaningful engagement by both the government and IBCA. The community needs to be treated with dignity and respect; it has suffered so much for so long, this has to stop.

51. The Inquiry's report made clear recommendations for the future, to date none of these have been successfully implemented. The Society has been keen to be involved in discussions surrounding the implementation of the recommendations but there has been a distinct lack of engagement or approach to us. For example, we are now part of the working group for the implementation of Recommendation 9, but we were only included after UKHCDO pointed out that there were no patient representatives as part of the working group. As far as we are aware, there has also been no community engagement in respect of the recommendation for memorials (Recommendation 2). We have written numerous letters in respect of this lack of engagement to the Paymaster General, see Exhibit WITN6392298. The government provided a response to the Inquiry recommendations on 17 December 2024 and stated that "*The membership of the steering committee will reflect the experiences of all routes of transmission, those infected and affected and will contain representatives of all of the UK's administrations*".

52. The funding for Recommendation 9 needs to be made available immediately to NHS England based on the needs of the recent peer review of haemophilia centres to ensure that the proper level of treatment and care for people with bleeding disorders can be provided as a matter of urgency. Funding needs to be provided to cover the costs of moving to recombinant products for all bleeding disorders where they are available, filling gaps in resources at haemophilia centres and setting up networks this should not have to be found from existing NHS resources.

53. Recommendation 10 stated "*the following charities receive funding specifically for patient advocacy: the UK Haemophilia Society; the Hepatitis C Trust; Haemophilia Scotland; the Scottish Infected Blood Forum; Haemophilia Wales, Haemophilia Northern Ireland and the UK Thalassaemia Society*". None of us have received any funding to date, despite being expected to conduct increased advocacy for our members in light of the situation as described above. We have been requesting funding from the Paymaster General for many months (see Exhibit WITN6392299 as an example) to no avail.

54. When laying the relevant regulations before parliament, it appears that certain incorrect decisions had already been made and, as a result of the wording of the regulations, these incorrect decisions cannot be overturned. For example, the Cabinet Office published a Draft Infected Blood Compensation Scheme Regulations 2025 Factsheet in January 2025. This factsheet states "*Because of the way the Victims and Prisoners Act 2024 works, the Scheme has to be set out in law. This law has to provide IBCA with all of the precise detail It needs to assess claims and make payments to everyone eligible for compensation. This is why these new laws will be longer and more complex than the first laws"*. The Society is concerned that by putting all of the precise details in legislation this in fact ties the hands of IBCA to the extent that it becomes an implementation body and not a wholly independent entity, see Exhibit WITN6392300.

55. The most important step of all is that government and IBCA simply need to ensure that compensation is paid as efficiently and quickly as possible to those that are eligible. There are 4,600 IBSS beneficiaries. Simplification of the evidence required to prove severity and date of infection could allow these people to access at least their core compensation almost immediately.

56. In summary there needs to be funding, engagement and progress.

Section 3: Reflections

57. The Society campaigned for many years for the Inquiry and also compensation. The overriding message we are hearing from our members and the community is that the culture needs to change. Sir Brian was clear in his final report that the government has to accept responsibility and there was a strong message that future governments needed to learn from the mistakes of the past and act with a strong sense of candour. Sadly, things have not changed. This government needs to make strides to change the culture and attitude towards the community and ensure that there is meaningful engagement.

58. We will obviously do everything we can to support those infected and affected in the community we have represented for 75 years this year. However, the Society is now on its knees in many ways. The staff and trustees are exhausted as a result of the relentless queries and support required; however , alongside the concern for the infected and affected community is the concern for the future of the Society. The Society is in the worst financial position it has ever been in.

59. As a direct result of the energy needed to support the compensation scheme in the ways described above, the Society's staff have been unable to focus on their day jobs and matters such as fundraising have had to take a back seat. Consequently, events have been cancelled (for example Youth Camp which has run in some form since the 1980s). As at the date of this statement, the Society has approximately six months of working capital available to it. Unless something drastically changes in the next couple of months, the Society is at serious risk of not being able to celebrate its 76th anniversary in 2026.

Statement of Truth

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

Signed GRO-C

Dated ______7 February 2025

Table of exhibits:

Date	Notes/ Description	Exhibit number
30/01/2025	Example of community feedback	WITN6392289
June 2024	The Haemophilia Society submission on the proposed Infected Blood Compensation Scheme	WITN6392290
03/09/2024	Haemophilia Society Presentation from Compensation Update Meeting Webinar	WITN6392291
06/11/2024	Haemophilia Society Presentation from Wills Estates and Probate Meeting Webinar	WITN6392292
	Haemophilia Society Presentation to IBCA	WITN6392293
Various	Examples of support provided to APPG	WITN6392294

28/09/2018 26/01/2019	Letters from Haemophilia Society to MPs lobbying for specialist psychological support	WITN6392295
13/08/2024	Letter from Paymaster General to the Society	WITN6392296
19/11/2024	Transcript from House of Commons Debate	RLIT0002475
27/01/2025	Examples of telephone calls received from the community	WITN6392297
12/12/2024	Letter to Paymaster General from Haemophilia Society re lack of engagement	WITN6392298
04/09/2024	Letter to Paymaster General from Haemophilia Society requesting funding	WITN6392299
January 2025	Draft IBCS Factsheet 2025	WITN6392300