Witness Name: Lynne Kelly
Statement No.: WITN3988094
Exhibits: WITN3988095 – WITN3988096
Dated: 30th January 2025

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF LYNNE KELLY

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

I, Lynne Kelly will say as follows:

Introduction

1. My name is Lynne Kelly. My date of birth and address are known to the Inquiry.

2. I produced a statement on my campaigning activities in 2020 for the inquiry. This statement and the exhibit numbers, follow on from that.

3. I am the Chairperson of Haemophilia Wales. I have a family history of Haemophilia which spans three generations. I have 3 sons with Haemophilia.

4. I have been actively involved in lobbying for improved care and support since the mid -1990s. I became a committee member of Haemophilia Wales in 2003 and a Trustee of the Haemophilia Society in 2011, after the death of my cousin from Hepatitis C. I am Secretary of the Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly and sit on the All Wales Advisory

WITN3988094_0001

Group on Inherited Bleeding Disorders and the Haemophilia and Bleeding Disorders Alliance. In the Kings New Year Honours List 2024, I was awarded the CBE for services to people with Haemophilia.

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

5. The work I have been undertaking is outlined below.

a) <u>Communicating with members:</u>

6. I communicate on a daily basis with members of Haemophilia Wales as individuals and as a group and provide updates by email and post as meetings with the various bodies take place.

7. I receive feedback from over 300 infected and affected members with a wide range of difficulties. The evolving information provided by the Cabinet Office, which has been delivered in an ad hoc fashion over 2024 makes meaningful communication with my members a challenging task. Continued communication is, however, essential to ensure I can take the community's issues and concerns to future meetings with the Cabinet Office, IBCA, Welsh Government and the Wales Infected Blood Support Scheme. It is also necessary to ensure our lawyers are aware of, and informed by our views.

b) <u>Meetings with Government:</u>

8. There has been no meaningful engagement with the key decision makers in the Cabinet Office as Haemophilia Wales was excluded from the first series of meetings with Nick Thomas Symonds, Cabinet Office Minister, held on 15th August 2024.

9. The first meeting on 23rd May 2024 with campaigners was a virtual meeting chaired by a young woman from the Cabinet Office. A number of other civil

WITN3988094_0002

servants were also on it. I am afraid it was a total shambles, with various campaigners making points and – because they were so upset – speaking over each other. The civil servants looked to me like 'rabbits in the headlights'. They had no idea as to the depth of feeling in the victim community of the sometimes tricky relations between some of the victim groups. I am afraid they (the civil servants) didn't have much of a clue, and nothing came out of that meeting.

10. There then was a meeting with Sir Robert Francis ("SRF"), Jonathan Montgomery, David Foley, Robin Healy, Hannah Smallwood and Rachel Forster and some of the campaigning groups, on the 18th June 2024. This was a more polite and better managed meeting, but still no real information came from it. I asked for more clarity on how and when compensation would be paid and in particular, when the interim compensation payments for previously unrecognised victims would be paid through the existing support schemes recommended by Sir Brian Langstaff in his 2nd Interim Report on Compensation 5th April 2023. No answers were forthcoming.

11. There was another virtual meeting with SRF and campaign groups that I attended on 16th October 2024. David Foley ("DF") was on the call. I again found it very frustrating as nothing concrete came of it. Amongst the things I pressed on, were information about the supplementary route evidence, to be supplied for estates payments, appeal process, unethical research. SRF could not comment on any of these. We were told about the idea of a 'test' cohort of 20 cases being taken forward. I pressed specifically about legal support funding, but I was told there was no information about that.

12. On the 27th November 2024, there was a meeting of what is called the IBCA Communications Advisory Panel. We were not provided with any Terms of Reference and were told that decision making rested with the Cabinet Office. Campaigners voiced their concerns about the way in which the so-called engagement meetings were being conducted, the additional stress this was causing everyone, and the lack of information being revealed by the Cabinet Office. I am afraid it felt a waste of time. We have not even been told about a next meeting.

WITN3988094_0003

13. Our first meeting with Nick Thomas Symonds ("NTS") was held on the 11th of December 2024, 5 months following his appointment. Also present were Cabinet Office civil servants. It was a meeting of victim representatives from the devolved regions. We were allocated 4 minutes to speak. At this meeting I outlined our member's overriding concern that Sir Brian Langstaff's 2nd Interim Report on compensation of the 5th April 2023 is being ignored, and as such, the recommendations are being undermined by the Cabinet Office approach. I raised concerns as to the delay in the process, the fact that IBCA is not an 'arms-length' body and the Case Manager system which seems hugely bureaucratic and costly. I am afraid it felt like we were not listened to. We were told that there was no commitment to consulting with us whilst the government produced the latest set of regulations. He said that he wanted to deliver compensation quickly, but he gave no detail. None of our members' concerns were answered and the general lack of a visible process leads to the inevitable conclusion that the Cabinet Office officials are not working to further the stated objectives of the IBCA but are in meetings to protect the Cabinet Office/Government position.

14. On the 20th January 2025, I attended a meeting with James Quinault ("JQ") Director General at the Cabinet Office. A major matter of concern was that JQ would not move on my representations that Alder Hey Hospital in Liverpool (which North Wales members of my group attended) would not qualify for the unethical research award. We raised concerns as to how the scheme is being run by claims managers, and that such a system seems to make the process take ages to get up and running. We were told by JQ that they were recruiting and that there was 'no cap' on the 500 case managers to be recruited. All present also raised concerns as to IBCA not being an arms-length body (this is evidenced by the fact that we were discussing IBCA with the Director General at the Cabinet Office).

15. On the 30th January 2025, I joined our 2nd meeting with Nick Thomas Symonds (NTS), Cabinet Office Minister, James Quinault, Director General, and Robin Healy from the Cabinet Office. Also present were Haemophilia Scotland, The

WITN3988094_0004

Scottish Infected Blood Forum, Haemophilia Northern Ireland, Friends and Families Northern Ireland. The purpose of the meeting was for NTS to provide an update on the Government's intentions for the 2nd set of Regulations. NTS said the Regulations would be laid soon, they would be debated in the Commons and Lords. He said it was his intention that the Regulations will be become law by 31st March 2025, but this is not definite yet. He said the factsheet that was circulated to us only the day before the meeting was only a starting point and would be accompanied by an addendum report by the Expert Group explaining the rationale behind the decisions. This is illustrative of the point that no victim groups have any input into all this, wholly contrary to the recommendation of the inquiry. I again raised Haemophilia Wales overarching concern that Sir Brian Langstaff's 2nd Interim Report on compensation 5th April 2023 continued to be ignored, that BCA is not an Arm's Length Body ("ALB") as all decisions on eligibility criteria and Tariffs and appeals lie with the cabinet office, that there has been no meaningful engagement with the community so as to influence the shaping of the scheme. I find it odd why the 4631 currently registered with the devolved schemes were not already awarded compensation for the core route. We still await a decision on legal representation by our trusted legal representatives. We remain concerned that Alder Hey Hospital is excluded and asked for clarity that patients from Carmarthen, Swansea and Newport Haemophilia Centres will also be included in the unethical research award as Prof Bloom purchased all blood products via Cardiff Haemophilia Centre and those products were then distributed to the smaller centres across Wales. Nick Thomas Symonds said the current support schemes would transfer to the new IBCA early next year but there is no date agreed yet. We were told that IBCA are in discussion with legal providers but there was no commitment to fund our recognised legal representatives to assist with compensation claims or for assistance with interpreting the 2nd set of regulations. NTS said he had visited the new IBCA this week and met with caseworkers and the 3 user representatives. He said those living infected currently registered with one of the devolved schemes can apply for the core route and SCM equivalent and they will not need further supporting evidence. Those applying through the supplementary route will need additional clinical supporting evidence. Caseworkers will point people to where they need to get this proof. He said

WITN3988094_0005

appeals will be independent though the Court system. I believe he meant that it will form part of the first tier tribunal process which is supported by HM Courts and Tribunals Service (HMCTS). It is still not really clear and still seems a long way from the specialist, independent appeal process envisaged by SBL. He said when he was in opposition, he also was pushing for the implementation of Sir Brian Langstaff's interim report on compensation. He said there will be no hard cut off points for date of infection for Hepatitis B post 1972 and Hepatitis C post 1991 but evidence will be needed to progress a claim. He said that if further evidence was received on unethical research from excluded Haemophilia Centres, then this would be considered by the Cabinet Office. He confirmed that natural clearers would be entitled to compensation. There was a feeling of desperation from all the victim representatives, as we now have to report this back to our members causing further disbelief, distress, confusion and frustration.

c) <u>Providing details of the compensation application process to members:</u>

16. There is complete confusion about how and when applications for compensation will open. As limited information has been provided to the community about eligibility criteria, tariffs and legal assistance, this continues to be a source of significant stress to applicants and those unsure of their entitlement and discussing how this is to be resolved is a major part of my work.

17. In my opinion, the Interim compensation payment to the previously unrecognised has been made unnecessarily confusing from the start. Instead of implementing the process as per Sir Brian's 2nd Interim Report on compensation, no information or direction has been made available in the 18 months post the compensation report's publication. No clear direction as to eligibility, the evidence needed to progress a claim or guidelines on who and where the claims are to be directed has been provided, and the IBCA meetings and newsletters do not provide answers to any of these questions.

18. The community have been encouraged to register an interest with the IBCA, but it has not been made clear whether or not this is the registration process for their compensation claim, or simply 'signing up' for so-called updates. As it now stands at the start of 2025, in the absence of a clear process, it is 'assumed' that people will have to wait to be 'invited' to apply for compensation. (January 22nd update from IBCA says people will be invited. But how do they know who to invite if the affected person has not already had an interim compensation payment? Will those people just fall off the radar?)

19. A large proportion of my working week is therefore spent trying to reassure people and advise them to have as much evidence as possible to hand, to progress a claim for when details of the process are eventually communicated by the Cabinet Office.

d) <u>Communication with Members of the Senedd, Members of Parliament, Members of the House Lords, The Cabinet Office, The Infected Blood Compensation Authority and the Wales Infected Blood Support Scheme.</u>

20. Much of my work is trying to understand where the Cabinet Office objectives differ from the Inquiry's recommendations; articulating our concerns about the Government's amendments to the Victims and Prisoners Bill and understanding the Government position on setting the compensation criteria, tariffs and the appeal process as they are being developed piecemeal by Cabinet Office officials, without engagement with the community and expert UKHCDO clinicians. This confusion is compounded by the Government's appointment of 'the Expert Group' led by Sir Jonathan Montgomery, who by no stretch of the imagination, are experts in the history, detail and effects of the scandal and who at this late stage have not published details of their recommendations as they are "still being worked upon". This group was set up in secret before the public Inquiry Report. It was central to Sir Brian's recommendation that victims and their lawyers should play a key part in the construction of the scheme, but that never happened and 20 months after Sir Brian's 2nd Interim Report on compensation was published we have no legal or clinical panel and only last minute engagement with the community as this time last year, the Government

WITN3988094_0007

began to put the scheme and system together, in secret with the 'Expert Group' led by Sir Jonathan Montgomery.

21. Examples of The Cabinet Office alternative objectives is the position they have adopted on Interim Estate Payments, as opposed to previously unrecognised deaths. Issuing misleading declaration forms on 21st August 2024 for deaths before 31st December 1981), imposing changes to the chain of representation and applicants being told by the IBCA that claims would be approved, to then being told by the Cabinet Office they needed Letters of Administration before they could progress. These 'alternatives' to the Inquiry recommendations continue to sow confusion and foster an atmosphere that claimants will not be treated fairly.

22. I, therefore, spend considerable time liaising with my members and communicating our understanding of the above points such that we can present coherent arguments to Parliamentarians, Welsh Assembly Members, Cabinet Office, and the IBCA. This unnecessary work is a direct result of the Government's failure to adopt Sir Brian's recommendations.

e) Communication with clinicians, social workers who all appear confused.

23. At a Cardiff Haemophilia Centre meeting of the 1st of August 2024, Haemophilia Clinicians and also the Blood Borne Viral lead reported that they do not yet know what evidence will be needed for Hepatitis B claims, self-clearers and enhanced Stage 1 payments. At the Haemophilia and Bleeding Disorders Meeting of the 15th of January it was stated that there has been no interaction by the Cabinet Office/IBCA with the UK Haemophilia Doctors Organisation, UKHCDO.

24. One of the haemophilia nurses in attendance, was tasked with trying to provide evidence for one of the pilot compensation claims but said the IBCA caseworker compiling the evidence did not know what was needed and did not know what the Special Category Mechanism was.

WITN3988094_0008

25. A Cardiff Social Worker has been involved in progressing claims for the interim compensation payment and said, quote: "*you would need to have a law degree to work through the Probate applications*". It is, therefore, the opinion of the entire community, that The Cabinet Office are intent on excluding community representatives, our legal representatives and the haemophilia clinicians in order to minimise the claims.

f) <u>Communication with other campaign groups</u>

26. I meet with the Haemophilia Society, Haemophilia Northern Ireland, Haemophilia Scotland, The Scottish Infected Blood Forum, Friends and Families Northern Ireland to discuss Cabinet Office/ IBCA meeting objectives and outcomes. I also have a good working relationship with Birchgrove, CBC, Factor 8 and Tainted Blood.

27. Below is a list of the meetings and debates that I have attended during the course of 2024 with the Cabinet Office/IBCA/Welsh Government. This as I understand the position is only a selection of meetings that have taken place across the UK with upwards of thirty-two different groups in attendance.

28. I feel that it has been a battle to even be involved in some of the meetings. On 14th June 2024, I asked for Mary Grindley to be invited to the June meeting with Sir Robert Francis on 18th June, this was refused.

29. When I heard about the meeting with Nick Thomas Symonds, Minister for the Cabinet Office, on 15th August, I contacted Hannah at the Cabinet Office/IBCA as I assumed they had overlooked this (as they did when I did not receive the link for the earlier meeting with Sir Robert). I had no reply, so I told Catherine Cody at the Welsh Government and the reply was, that the Minister's stakeholder meeting is necessarily small. They included some UK wide organisations that broadly represent a full range of cohorts within the community. I then had a call from Hannah Smallwood at the Cabinet Office/ IBCA and I voiced my concerns that I had been excluded as the only charity,

WITN3988094_0009

representing over 300 Haemophilia and transfusion victims. The invitation to meet with Sir Robert as a Haemophilia Wales group in October was rescinded when I sent a list of attendees to the Cabinet Office. Again, I was the only Welsh representative at the meeting. Haemophilia Wales was not invited to the meeting with Nick Thomas Symonds until 11th December 2024. At this meeting, I again relayed our main point about Sir Brian's interim report being thrown in the bin.

30. The output of **all** of these meetings has to be communicated across the groups in an attempt to get a common understanding of the Government's position and response to the Inquiry.

31. This is not what was envisaged. What was envisaged and expected after 7 years of the UK's largest Public Inquiry, was that there would be a general acceptance of the Inquiry's recommendations, as the Inquiry had already engaged extensively with infected and affected and all evidence had been published. What was **not** expected, was the protracted negotiation by stealth with the Government that we are engaged upon.

    - 2nd of May 2024 John Glen met with Lynne Kelly Haemophilia Wales

    - 23rd of May 2024 Brian Williams, James Quinault, Robin Healy Cabinet office Technical Briefing meeting. Haemophilia Society, Scotland, Northern Ireland, Tainted Blood Factor 8 CBC.

    - 4th June Cross Party Group Meeting with Eluned Morgan Health Minister Welsh Parliament (Senedd)
    - 4th June Welsh Parliament Infected Blood Debate

    - 18th of June Sir Robert Francis, Sir Jonathan Montgomery, David Foley meeting,

WITN3988094_0010

- 24th July meeting with Catherine Cody, Welsh Government Policy Lead and Mary Swiffen-Walker Wales Infected Blood Support Scheme.

- 16th September IBCA meeting Emma Browne Cabinet Office.

- 16th October Sir Robert Francis meeting with David Foley Interim Chief Executive IBCA, Rachel Interim IBCA Engagement manager Emma Browne and Ellis IBCA engagement team. Martin Stone and Paul Kirkpatrick Friends and Families Northern Ireland, LK Haemophilia Wales.

- 23rd October meeting with Catherine Cody Welsh Government Policy Lead and Mary Swiffen-Walker, Wales Infected Blood Support Scheme.

- 27th November IBCA Communications Advisory Panel Meeting.

- 11th December Nick Thomas Symonds Cabinet Office meeting with Haemophilia Society, Haemophilia Scotland, Northern Ireland, Friends and Families Northern Ireland, Scottish Infected Blood Forum.

- 13th January meeting with Julie Morgan, Member of the Welsh Parliament/Senedd.

- 20th January meeting with James Quinault
- 20th January written Question Julie Morgan to Jeremy Miles Cabinet Secretary for Health Welsh, Parliament
- 30th January meeting with Nick Thomas Symonds Cabinet Office Minister.

g) Communication with the Infected Blood Inquiry

32. On the 5th December 2024 I was moved to write to the Chair of the Infected Blood Inquiry, Sir Brian Langstaff KC (SBL). This summarises my main concerns. A copy of the letter is exhibited at (WITN3988095).

33. From the 20th and 30th of January, James Quinault and Nick Thomas Symonds met all 32 groups but this engagement has come too late, in order to influence Government in any meaningful way. What all this really is, is a briefing exercise to tell us what has been done and decided. In no way are we inputting into anything either policy wise or operationally.

34. The Government will record they have extensively consulted and the record will show that a large team of Cabinet Office officials at great cost have trafficked the length and breadth of Great Britain.

35. Notwithstanding the volume of meetings, the input from the Cabinet office is to listen, say nothing or as a minimum parrot 'the new line(s)' and report back to centre.

36. In short, it feels an exercise high on cost and low on delivery. There is no suggestion that the fundamental problems with the scheme will change.

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

37. Haemophilia Wales Trustees provide support to over 300 members and this will continue until justice is done. The charity is funded by donations and the trustees and members are all unpaid volunteers. No support has been provided by external bodies.

38. I have personal contact with all our members, both haemophiliacs and those infected through transfusion. I believe I am transparent in my communication with the members and trusted to carry their wishes forward and represent them

WITN3988094_0012

at meetings. The system we have developed over many years of campaigning is one of mutual support where no party is excluded. This enables Haemophilia Wales to operate in the way it does to successfully lobby their Members of the Senedd and MPs without external funding.

39. I have support from our lawyers: Michael Imperato at Watkins and Gunn is trusted by Haemophilia Wales and has been instrumental in advising us on legal matters on an unpaid basis prior to the Inquiry, and as our recognised legal advisors during the Inquiry, they now continue to provide sound guidance and advice during the current discussion with the Cabinet Office. They additionally keep us informed of the dialogue with other lawyers working with the UK campaign groups and what the general consensus is regarding ongoing legal representation of claimants. They do all this pro bono. It is only by Michael (and his teams) good grace, and willingness to help without charge, that we receive this valuable support. I am always worried that they will tire of providing all this free help and we will be cut adrift with no legal support.

40. Members of the Senedd: I and the members have weekly contact with a variety of Senedd members to ensure the constituents' voices and views on the development of the compensation plan are heard.

41. Julie Morgan: My Member of the Senedd for Cardiff North and previous Chair of the Cross Party Group on Haemophilia and Contaminated Blood is well known and trusted by our group. She has been involved since the 1990s as an MP and a Member of the Senedd. A strong respected political voice and consistent supporter of our cause asking questions in the Chamber and joining Cross Party Group Meetings. We maintain regular contact and her most recent intervention on our behalf has been to pose a question in the Senedd on the 20th January (See appendix 3) found at exhibit (WITN3988096) for the question and response. The response is instructive as it establishes that 'the new line to take' regarding the methodology of the compensation role out has already been embedded in the stock government responses of Welsh Government.

WITN3988094_0013

42. We maintain a regular contact with Rhun Ap Iowerth Member of the Senedd, Plaid Cymru, Anglesey and he regularly articulates his constituents' views and the objectives of the Cross Party Group on Haemophilia and Contaminated Blood in the Senedd, reinforcing the need to implement Sir Brian's recommendations.

43. Haemophilia Cardiff staff: The Cardiff Haemophilia staff have proved invaluable over 2023/24, in providing assistance to patients, families and bereaved families needing more information on clinical notes, National Haemophilia database notes and details on a range of infections. They have been consistently supportive of our efforts over the years to get to the truth even when that may be a difficult truth to understand.

3. **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 have experienced it.**

44. We have had no input into decision making regarding compensation or the running of the scheme. This is probably the single biggest fundamental flaw in the whole process and undermines everything that has happened since the public inquiry reported.

45. The engagement meetings with the Cabinet Office and the IBCA have been ineffective in that no answers to our questions on the basic principles of the compensation process, or indeed the process itself have been provided. The IBCA default position on all the key matters is 'we are awaiting direction from the Cabinet Office'. The responses from The Cabinet Office are similarly vague on points of principle which instead of being openly discussed in meetings are 'floated' out in communications as if they have been debated and thoroughly discussed and agreed with the community. Which they have not.

46. An example of this is the position on legal representation and the appeals process. The narrative on these points has changed on three separate

WITN3988094_0014

occasions from meeting to meeting. Following meetings, the community across the UK is left in the dark and the burden falls on campaign group leaders to reassure members about the long-term outcome and encourage everyone to maintain a campaigning mindset. Similarly, the only thing that has trickled down to the devolved administrations is 'the new line' of "we are starting small and scaling up", Welsh Government and WIBSS are not in a position to answer questions.

47. The record will show that there has been a generous allocation of Government staff time to the numerous meetings scheduled out in my submission. However, hosting a meeting is not necessarily a consultation unless proposals/ideas/issues are tabled for discussion, and not already been decided, in secret, in advance. It is therefore fair to say that there has been no meaningful consultation or engagement and therefore no involvement in any part of the decision-making process. It cannot even be said that the questions tabled, led to discussion which informed decisions as the questions were not responded to; "We are waiting for direction from the Cabinet Office".

48. Haemophilia Wales was not invited to meet with Nick Thomas Symonds, Cabinet Office Minister on 15th August 2024. During this period there were clearly meetings taking place behind closed doors to decide how to present the decision **not** to implement Sir Brian's recommendations as he set it out, and instead, to bring Jonathan Montgomery's secret expert group to the fore of the process. No one to my knowledge was communicated with during this critical time when decisions on the formation of a plan to deliver compensation were essential. This wholly goes against a main plank of Sir Brian's recommendations that victims should inform the new setting up and structure of the new scheme.

49. While I was invited to meet with Sir Robert Francis on the 18th of June and again 16th of October 2024, I was not invited to meet with Nick Thomas Symonds until 11th December 2024. Haemophilia Wales have not therefore been invited to participate in any of the decision-making process or been asked our opinion on the emerging system of compensation.

WITN3988094_0015

50. We have been asked by the Cabinet Office and the IBCA to encourage our members to register an interest with the IBCA which to their surprise is not the registration of their compensation claim, nor is it a registration of an interest to participate in the devolvement of the compensation process, but a mailing list for a newsletter which does not answer their main issues.

51. The community still do not know how and when they are to properly register their claim 19 months after Sir Brian's 2nd interim report on compensation.

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

52. The principal concern of myself, our Trustees and Haemophilia members (both Haemophilia and transfusion infected and affected) and the key message which I have consistently relayed to Government and the IBCA that the Government are not implementing Sir Brian Langstaff's 2nd Interim Report on compensation.

53. I am in a unique position, as I am the nominated representative of Haemophilia Wales Charity, and we have consensus on this from all our members. I confirm that I have stated this at every Cabinet Office/IBCA meeting. Unfortunately, our principal concern fails to be recorded in any official minutes. I am the only Welsh representative of both Haemophilia and transfusion infected and affected and I believe our principal concern is being deliberately ignored. There appears to be deliberate attempts to cause confusion by the sheer quantity of Cabinet Office/IBCA staff at meetings who evidently are not decision makers. Long-standing Cabinet Office staff, such as Brian Williams, Policy Lead at the Cabinet Office, has attended our meetings with previous Paymaster Generals prior to the Inquiry. He knows that the community want Sir Brian Langstaff's recommendations on compensation to be implemented as a whole. He was at the Inquiry on the day of the Report in May and was at the Government Technical Briefing meeting on 23rd May. He has now seemingly disappeared.

54. The Cabinet Office have not consulted with the UKHCDO, so it is unclear how they are training their 500 case workers to ensure that they get compensation claims correct.

55. I am concerned that IBCA is not 'arm's length'. Everything about IBCA seems to me to be determined by civil servants (and thus, the Government). It seems to me that IBCA is an agent of the Government. This was the concern and issue victims had with the Skipton Fund. On the 27th November 2024 at the meeting of what is called the IBCA Communications Advisory Panel, we were told that all decision making rested with the Cabinet Office.

56. I am very concerned about the appeal process, which appears to have been given little thought and certainly no engagement. The proposed 1st Tier appeal process is also a cause for concern as if the application is unsuccessful, applicants will not have any funding for legal support to take appeals forward. When I asked about this at the meeting with James Quinault on 20th January, he said that appeals panels/ judges were being trained. How much is all of this costing? If our lawyers were representing us, then claims would be settled fairly and quickly.

57. In his recommendations, Sir Brian emphasised the need for a Specialist, Independent Appeal Tribunal. There is no sign of this.

58. Not being an ALB, it is evident that all aspects of the scheme, whether it is structural, or operational, are driven by the Cabinet Office civil servants. The structure of IBCA is a general concern as well. The Government have appointed a number of non-executive directors, three of whom are audit-based accountants. I have heard it likened to "the MacFarlane scheme on steroids." It is bizarre that there was no room on the board for anyone who had any background of working with campaigners and victims. We feel totally sidelined.

59. A major concern is the way access to legal advice is so limited. At present, any help we are given is generally through the good grace of our lawyers doing it

for free. There seems to be a distrust of our lawyers, lawyers who have acted for us and the community, through thick and thin, for nearly ten years now. At the recent meeting with James Quinault, he said the Government were procuring other law firms services as well as recognised legal representatives if they wanted to be involved. I said that this was not acceptable as our members trusted our legal representatives and would not want to be advised by new lawyers they did not know and trust. I felt this approach undermined the importance of our long established recognised legal representatives. I was also astonished when I heard that the Government/IBCA were seeking at one point to gag our lawyers, not allowing them to speak to us about any concerns they – the lawyers – had with the scheme.

60. I am very concerned with the establishment of a corporate structure and a cottage industry of IBCA caseworkers who can only refer to Sir Jonathan Montgomery's Expert Report. We were told at the Haemophilia and Bleeding Disorders Alliance meeting on 15th January that there has been no engagement with the UKHCDO by the Cabinet Office and that Haemophilia Doctors and nurses assisting with pilot applications are having to liaise with caseworkers who have no knowledge of the Special Category Mechanism, Hep B, natural clearers. This is a complete waste of everyone's time and money when our trusted legal representatives hold this evidence already. It seems bizarre that costly case managers are to start a case off and gather information, when the simplest, cheapest and quickest way would be to allow applicants and their lawyers to pull together the documents and history that already exists. That would swiftly kick start the process off.

61. The above feeds into one of the biggest concerns, that this whole process is going to take forever and come with a huge administrative cost.

62. All issues raised at engagement meetings with Cabinet Office officials, Sir Robert Francis and the IBCA remain unanswered either verbally or formally. In any event these officials constantly defer to the position of "we are waiting for direction from the Cabinet Office".

WITN3988094_0018

Specifically questions critical to the compensation process such as:

- What is the compensation process?
- What can I expect to receive?
- Who is eligible?
- How to register?
- How to progress a claim?
- What is the timetable to make compensation payments to the 4671 people who are already registered with the Infected Blood Support Schemes?
- Why I cannot retain my legal representation with my trusted solicitors?
- Why can't they start off my claim?
- What is the appeals process?
- What is a case worker/claims manager and how are they trained to provide the necessary support to claimants? How will they obtain further information if they do not know what they are looking for?
- Widows registered after April 2025 - Where do they stand?

63. We have pressed for a simple statement to be issued to the community setting out answers on the above questions and importantly how decisions on the following have been made, this statement has not been forthcoming.

64. It feels that the Government and IBCA are trying to close down, shut out, the victims groups and their lawyers, rather than work with them. The lack of concrete information from the Cabinet Office requires new 'lines to take' to be developed to shore up the inadequacies of the system. Below is an extract from PR Monthly dated the 27th of January 2025 written by Evie Barrett about the appointment by IBCA of a new PR company.

65. According to a document available via the Gov.uk Contracts Finder site, Four's brief from the IBCA covers raising awareness among affected communities, as well as ensuring media coverage is *"well balanced"*.

WITN3988094_0019

66. The document states: *"We would also expect you to lead on combatting negative press and media, developing defensive lines and changing the narrative to support the good and positive work we have been established to do."*

67. Regarding media engagement, Four has been appointed to *"proactively sell-in"*, *"encourage positive reporting"*, and *"lead on lines to take"*, working closely with the Infected Blood Compensation Scheme's in-house press office.

68. The brief also covers crisis comms, advocate and stakeholder engagement, and case study curation.

69. Beyond the question of why the Cabinet Office believes spending 250k of the compensation fund on a PR campaign is ethical, and posing the question why is a PR campaign necessary, if what they are doing is aligned to the needs of the community, this content speaks precisely to the failures in the Cabinet Office's approach. This is the heart of the problem. The Cabinet Office have refused to implement the Inquiry's findings and seek to invent a system designed to restrict payments. All policy and operational development has been undertaken in secret, there has been no co-production with victim groups and their lawyers. Now, given the upset and discontent this approach has caused, they need PR to help develop and sell the 'new lines to take'.

70. It is not acceptable that a briefing document issued by the Cabinet Office in late 2024 talks of *"developing defensive lines and changing the narrative."*

71. Haemophilia Wales and our members demand to know:
    - Who wrote that brief?
    - Who made the decision to sign off the PR contract?
    - Where is the Non-Executive team at IBCA in this process and were they consulted?

WITN3988094_0020

72. Has anyone involved in this decision read the Inquiry findings and what on earth is the mentality of the leaders of a department, with the recommendations of a seven volume Public Inquiry on their desk, in allowing this to be sent out. Is it that even before the ink is dry on the PR contract the names of the persons responsible are already a mystery, lost in the lack of records and accountability.

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

73. Haemophilia Wales is entirely funded by donations and represents over 300 infected and affected Haemophilia and transfusion patients, families and bereaved families. We are unpaid volunteers with no staff, and I run the charity on my own with the support of the trustees. I have worked hard to establish a personal connection with all our members and am trusted by them to provide support and to raise issues on their behalf. I have a unique insight into the impact of the confusion and suffering within the community not only through the contact with our members but also through the affected within my own family. The suffering which has been experienced over the decades has been exacerbated by the Government's handling of the compensation question since Sir Brian's 2nd Interim Report on compensation was published on 5th April 2023.

74. We continue to personally witness the deaths of the ill and elderly infected and affected throughout this time. They sadly die without justice being served and as it took 18 months (following Sir Brian's compensation report April 2023) for applications for the interim compensation payment for deaths previously unrecognised, this came too late for some.

75. The Cabinet Office continued to seize the opportunity to confuse and delay interim payments with changes to the chain of representation; the first payments were not made until December 2024.

76. The additional time taken to assist members interpreting and trying to process the Cabinet Offices/IBCA's position in the absence of proper communication

from them, coupled with an absence of process and timetable is extremely time consuming. Add to this the unaddressed issues of legal advice and assistance with complex Probate and Letters of Administration, which is topped off with the recent knowledge that after three decades they are to be *invited* at some unknown point in the future to make their claim to conclude this life changing disaster, is so incomprehensible I would challenge anyone to deny that the daily work load of Haemophilia Wales is not debilitatingly stressful, personally, and to the members who have already been so damaged by 40 years of the same shameful behaviour by successive Governments.

6. 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.

77. There is a clear lack of meaningful communication and useful detail from the Cabinet Office which is causing enormous distress to the infected and affected as their questions continue to go unanswered. The leading charities and campaign groups workload has increased due to the volume of calls and requests for clarity from the membership. As we do not have a clear message to communicate this leads to anger and confusion within the community and additionally sows confusion between the campaign groups as they seek to interpret what limited information is available.

78. This lack of transparency has sent the community into chaos as the lack of honest clear communication and process were at the heart of the findings of the inquiry and 'history repeating itself' is what appears to be happening.

   a. This failure of communication and process therefore undermines:

      i. the belief in the Inquiry's ability drive the Inquiry findings into actions
      ii. and in turn, the community's willingness to believe the Government

iii. Haemophilia Wales' work as they feel answers are not forthcoming.

The community want the implementation of Sir Brian Langstaff's 2nd Interim Report on compensation and not Sir Jonathan Montgomery's recommendations based on a few case studies and decided upon in secret with no victim input.

b. There is also suspicion that this is a deliberately long drawn out process because so far only a handful of people have been paid through the IBCA. Saying that they are starting small to make sure they get it right is not a defence for not communicating your intent and process.

c. There is also more than a suspicion that the recommended safeguards have not been put in place, such as right of appeal, legal representation, consultation with experts at the UKHCDO.

7. Are there any particular steps or measures which you consider could be taken by Government, IBCA or both to alleviate any detrimental impact upon you, and/or the infected and affected communities? If so, please set them out.

79. In order now to improve the situation, I would wish to see the following;

- I would like the Government and IBCA to properly implement Sir Brian Langstaff's 2nd Interim Report on Compensation, in order to gain the trust of the community. They should do what Sir Brian Langstaff originally said, which is to redesign the structure, so that victims and their representatives have an input. It cannot be too late to reset the system. Some may say this will cause delay, but things cannot be going as slower than they are at the moment.
- Instruct our recognised legal representatives to assist with starting off claims instead of claims managers.

WITN3988094_0023

- Make payments immediately through the core route to the 4,631 already registered with the UK support schemes with the supplementary route available to those claiming additional impact. 4000 gave evidence to the Inquiry.
- Start registering the remaining affected group with IBCA and start progressing their claims.

8. Conclusion

80. Worryingly as the recommendations of Sir Brian's Report have not been taken up by The Cabinet Office, a distance grows from its publication. With new administrators starting to populate the Cabinet Office/IBCA and as the case worker army grows, 'the new line to take' seems to be taken from Jonathan Montgomery's report. The Inquiry findings are in the back office somewhere, but as the findings have not been implemented, the report and the evidence of 4000 people is set aside and devalued, and so the mistakes that were so difficult to record that it took 7 years to write them down are being remade by a new generation of administrators. As stated above we have reached a position where things are so bad in respect of trust between the government/IBCA and the victim community that a PR company has been brought on board by the government/IBCA to *"develop...<u>defensive</u> lines and <u>change)..</u> the narrative."*

81. It feels that some of the fundamental failings of the State – and in particular the Civil Service and Politicians - are being revisited on us all over again. Sir Brian Langstaff was very critical in the Inquiry report of the Civil Service taking a line early on which they would not move from. That is exactly what has happened here, with the compensation scheme and apparatus being designed in secret with no input from victims and now, as its failings are exposed, a refusal to move or to take on board suggestions for change.

WITN3988094_0024

Statement of Truth

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

Signed GRO-C

Dated 12.2.25

WITN3988094_0025

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**
5/01/25	Letter from Lynne Kelly (LK) to the Chair of the Infected Blood Inquiry, Sir Brian Langstaff KC (SBL). Summarising LKs concerns.	WITN3988095
20/1/25	Question posed in the Senedd on the 20th January 2025 by Julie Morgan MS	WITN3988096

WITN3988094_0026