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Haemophilia Scotland)
Statement No.: WITN7754001
Exhibits: WITN7754002-WITN7754028
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INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF HAEMOPHILIA SCOTLAND

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

I, JOHN DEARDEN, will say as follows, on behalf of Haemophilia Scotland:

1. Haemophilia Scotland is a Scottish incorporated charitable organisation registered with the Office of the Scottish Charity Regulator under reference SC044298. Our principal office is at The Eric Liddell Centre, 15 Morningside Road, Edinburgh EH10 4DP. Our primary role is to further the health, education, wellbeing, and the social and economic welfare of all those in Scotland with a bleeding disorder and their families. In this we support individuals and their families, arrange events, provide information and advocate on their behalf.
2. I am Chair of Haemophilia Scotland, a position I have held since 24th August 2024. Prior to that, I was Co-Chair of the organisation with William (Bill) Wright from 1st April 2023. William Wright, who the Rule 9 request was also sent to, ceased to be Co-Chair and Trustee of Haemophilia Scotland on 24th August 2024. He remains involved in the work of Haemophilia Scotland in an advisory role in relation to infected blood.

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

3. The terms of the Infected Blood Compensation Scheme are of great interest and a matter of concern to many of our members. We have sought to understand and contribute to the debate and discussions relating to the compensation scheme where we have been allowed to do so. As an organisation we were a core participant in the Infected Blood Inquiry and, like many, keenly awaited announcement of the Inquiry's recommendations on 20th May 2024. The recommendations published by the Inquiry instilled a sense of elation in the infected blood community and were seen as vindication of many years campaigning. The Inquiry provided an opportunity for individuals to tell their stories and to be involved in exposing the harm that had been caused through infected blood and blood products. Since May 2024 we have been actively involved in seeking to influence the terms of the compensation to be paid to victims of the NHS infected blood scandal.
4. Publication of the Inquiry report was quickly followed with statements made to the Commons by the Rt Hon Rishi Sunak MP (then Prime Minister) on 20th May 2024 (RLIT0002476) and the Rt Hon John Glen MP (then Paymaster General) on 21st May 2024 (RLIT0002477) who announced details of the proposed compensation scheme. In his statement to the House John Glen referred to the meetings he had held with over 40 representatives of the infected blood community across the country. This included one with representatives of Haemophilia Scotland and the Scottish Infected Blood Forum in Edinburgh on 10th May 2024. We found the meeting informative and reassuring of the government's intentions. John Glen showed genuine interest in putting right the wrongs of many years and expressed a willingness to meet further with community representatives and to hear their views on the proposed compensation scheme.
5. From the immediateness of the government response in May 2024 it was apparent that, behind the scenes, the government had been working with the Infected Blood Expert Group appointed by the Paymaster General in January 2024 to draw up the government's response to the Inquiry recommendations in the second interim report.

All of this was with no consultation with the infected blood community, or regard to the involvement of the infected community in decisions which affect them as recommended by the Infected Blood Inquiry. As noted in the Expert Group's final report under "Acknowledgement and Thanks" the report author stated:

"Our terms of reference did not permit us to take evidence directly from members of the infected community. We have done our best to take note of evidence received by the Inquiry and we have drawn on members' insights from their professional work. Had time and the restrictions of confidentiality permitted wider consultation, then we would have found that helpful." Essential elements were therefore sadly missing from the consideration given by the Expert Panel – the voice of the patient, the infected and the affected were not heard.

6. The Inquiry's recommendations made on compensation had been announced on 3rd April 2023 in the Chair's Second Interim Report on Compensation. The government had declined to progress these recommendations at the time deciding instead to await the Inquiry's full report. It was therefore just over a year before the recommendations made saw a response, despite the urgency for action set out in the interim report. Throughout this period there was no engagement between the government and the infected blood community.
7. In the days that followed publication of the Inquiry's final report we were inundated with information and activity. The announcements in Parliament, publication of a variety of government policy documents (some of which have subsequently been amended) caused confusion and uncertainty. The announcement made about the compensation scheme brought with it anxiety over what would happen to the Support Schemes and whether individuals would lose their entitlement to regular financial support payments, on which many relied.
8. Announcement of a general election brought a further dynamic to the situation with the hasty approval of the Victims and Prisoners Act 2024 on 24th May 2024 as part of the Parliamentary wash-up programme before dissolution of Parliament all happened within days. The Victims and Prisoners Act was important as it laid the foundation for the payment of compensation and the creation of the Infected Blood

Compensation Authority. Because of the rush to approve the Act there was little opportunity to seek to influence its content, or to allow the usual Parliamentary scrutiny. Provisions within the Act also required the initial statutory instrument governing the compensation scheme to be approved within 3 months of the approval of the Act i.e. by 24th August 2024.

9. On 21st May 2024, our then Co-Chair, Bill Wright, was invited to the Scottish Parliament to hear a fulsome apology from the First Minister, John Swinney MSP, on behalf of the Scottish Parliament to those in Scotland harmed by the infected blood scandal. This reinforced within Scotland the value of the Inquiry report.
10. Haemophilia Scotland was invited by the Cabinet Office to attend an on-line technical briefing on the legislation on 23rd May 2024, just days after the publication of the government's plans. Unfortunately many of us had had little opportunity to fully assimilate the information and even less opportunity to consult our legal advisers. Organisations were generally allowed to send one representative plus a lawyer as an observer (who was not allowed to speak). This was attended by many interested voluntary, charitable and lobby groups. About 40 in total. The numbers involved and use of the event by some organisations to further their own specific objectives made the meeting unmanageable and very little was learned of the government's plans, other than what had been published. The meeting was strictly a briefing on what had been decided.
11. The government approach has been one of organising either large meetings, or a series of meetings involving multiple participants, with little time for the infected community to contribute. Over time there has been variation in the individuals and groups invited to attend, with no clarity on how groups and individuals were selected.
12. On 27th May 2024, jointly with the Scottish Infected Blood Forum, we wrote to the John Swinney MSP, First Minister for Scotland, on the Scottish Parliament response to the UK Infected Blood Inquiry (WITN7754002) expressing appreciation of the apology offered by the Scottish Parliament and drawing attention to some of our fears over the announcements made over recent weeks. These included:

- The threat to the future of the Scottish Infected Blood Support Scheme (SIBSS)
- That the Scottish government's repeated undertakings that support payments were for life may be at risk.

13. The response we received on 31st May 2024 from John Swinney MSP (WITN7754003) contained affirmation that the First Minister was committed to ensuring victims got fair compensation, that the Minister for Public Health and Women's Health, Jenni Minto MSP, was committed to doing what she could to ensure the views of the infected and affected were properly taken into account by the UK government and IBCA in the design of the compensation scheme. Also that no one would be financially worse off as a result of the compensation scheme. In this connection, we note that under the UK government compensation scheme as currently drawn the widows/partners of an infected person who dies after 1st April 2025 will be significantly worse off than if the infected person had died at an earlier date. Where death occurred before 1st April the widow would have had an entitlement to a percentage of the support payments his/her partner received. After 1st April this option is not available.
14. Following publication of the Inquiry report and the related announcements from government, our organisation and others like the Haemophilia Society and Haemophilia Northern Ireland received significantly increased approaches from our members looking for help in understanding what was proposed by way of compensation and the process involved. In the absence of information from IBCA and confusing documentation from government, individuals turned to us for help. As a small organisation with only two full-time staff we struggled to respond. The support we provided was to the detriment of our other work. A situation that cannot be sustained without significant risk to the future of our organisation.
15. On 30th May 2024 jointly with the Haemophilia Society and Haemophilia NI we wrote to the Paymaster General, the Rt Hon John Glen MP, (WITN7754004) asking that he fulfil the terms of recommendation 10 of the Inquiry report to provide advocacy funding for haemophilia based charities and other similar bodies. We received a response on 3rd July from the Head of Parliamentary and Correspondence Team at

the Cabinet Office (WITN7754005) which detailed the recent events relating to infected blood and confirming that government would review the Inquiry's recommendations. As described below, we received no further comment from government on recommendation 10 until December 2024. We have continued to help our members as best we can. We have used our links with other charitable bodies and campaign groups to develop our understanding of the compensation scheme, but very much on a self-help basis. It became apparent at a recent meeting on 11th December that the government had done nothing about the Inquiry's recommendation 10.

16. On 13th June 2024 we, along with some 28 campaign groups and individuals, were invited to a series of on-line meetings with Sir. Robert Francis, Interim Chair of the Infected Blood Compensation Authority, David Foley, Interim Chief Executive of the Authority and Sir Jonathan Montgomery, Chair of the Cabinet Office Infected Blood Expert Group. Sir Robert had been asked by the government to engage with the infected blood community over the election period on the compensation scheme that has been proposed on 21st May. Haemophilia Scotland was in a group of 6 organisations representing those with a bleeding disorder and the Scottish Infected Blood Forum. The meeting lasted two hours. In total there were 4 groups, so the total time devoted to face to face engagement amounted to no more than 8 hours on a subject of tremendous importance to thousands.

17. We were invited to make additional written submissions after the meeting. I provide Haemophilia Scotland's submission from the Co-Chairs of Haemophilia Scotland dated 28th June 2024 (WITN7754006) to illustrate the scale of concern. This submission had to be prepared within a tight deadline which imposed considerable pressure on our small organisation. We were grateful for the assistance provided to us by Thompsons Solicitors in the preparation of this submission.

18. In response to this engagement we received via e-mail from IBCAFeedback@cabinetoffice.gov.uk a short two page summary of the points raised within the meetings on 28th June 2024 (WITN7754007). We received a slightly more detailed summary via e-mail from ibiresponse@cabinetoffice.gov.uk on 2nd July 2024 (WITN7754008). Neither fully reflected in detail the range of issues discussed.

19. The General Election Polling Day was on Thursday, 4th July. The outcome was a majority for the Labour Party who were asked by His Majesty, the King, to form a government.
20. On 8th July Haemophilia Scotland wrote to the new Minister with responsibility for the government's response to the Infect Blood Inquiry – Minister for the Cabinet Office, Nick Thomas-Symonds MP (WITN7754009) drawing attention to the necessity within the Victims and Prisoners Act 2024 to put into place regulations on the compensation scheme by 24th August 2024. We expressed our view that the scheme as then proposed fell considerably short of what the Infected Blood Inquiry and the Sir Robert Francis Framework Report had recommended. We were critical of the lack of consultation with the infected community in preparing the scheme. We reminded him of the words from the IBI report that “decisions about those who should receive compensation are not made without them”. Also that the engagement undertaken by Sir Robert had been too constrained. The summary of the issues raised through engagement did not in our view reflect the concerns and failings set out in the meetings held. We urged the new government to pause and reflect on the many comments made and to ensure we were presented with a workable and fair scheme.
21. On 26th July 2024, the Minister for the Cabinet Office, Nick Thomas-Symonds, wrote to Haemophilia Scotland (WITN7754010). In the letter he said that “Delivering justice, including compensation to the infected blood community is one of my driving principles”. He also told us that applications from estates who were to receive a £100,000 interim payment would open in October (some three months away). He made no reference to our letter of 8th July.
22. On 2nd August Haemophilia Scotland wrote again to Nick Thomas-Symonds, expressing our concern at the lack of response to our letter of 8th July 2024 and the failure of meaningful engagement with our and similar organisations (WITN7754011).
23. Also on 2nd August 2024 Haemophilia Scotland wrote to Jenni Minto MSP as Minister for Public Health and Women's Health at the Scottish government (WITN7754012)

seeking her assistance in ensuring that the views of the infected blood community in Scotland were fully reflected in discussions taking place between the UK government and devolved governments. We received a supportive response from the Scottish Minister on 19th August 2024 following a face to face meeting on 16th August 2024 (WITN7754013).

24. On 15th August the Minister for the Cabinet Office, Nick Thomas-Symonds, invited 7 organisations associated with infected blood to an on-line meeting to hear the outcome of the engagement on compensation undertaken at the government's request by Sir Robert Francis. Haemophilia Scotland and Haemophilia Northern Ireland were two of many organisations excluded from this announcement. Haemophilia Scotland and Haemophilia Northern Ireland wrote a letter on 15th August 2024 to the Minister for the Cabinet Office, Nick Thomas-Symonds, expressing our disillusionment over this move (WITN7754014). We found the move to be divisive, isolating us from organisations we had regular contact with over the Inquiry. We called for a clear rationale from government on the approach to be taken on the recognition of consultative bodies. It was of particular concern that issues affecting the devolved nations were being discussed without our being present.
25. On 16th August we became aware that the report of Sir Robert Francis KC on his engagement with the infected blood community had been published by government. Sir Robert's report had been completed on 12th July but not published until a month later. The government had accepted all but 5 of the 74 recommendations made by Sir Robert and proceeded at pace to put those recommendations into the Infected Blood Compensation Scheme Regulations 2024 which were made on 22nd August. If anyone disagreed with the recommendations there was no opportunity to make their views known. As an organisation we welcomed the recommendations made by Sir Robert generally as improving the terms of the compensation scheme, but noted that there were still many uncertainties over the scheme, particularly for those affected and those wishing to make a supplementary route claim. These uncertainties would not be resolved until the Spring of 2025. This was a great disappointment to us and a source of frustration to our members. They had seen progress with the publication of the Inquiry report, but were now being told it would be months before anything happened.

26. We took the opportunity in September 2024 to prepare a briefing for Scottish Members of the Westminster Parliament and other interested parties on what had happened since the announcement of the IBI recommendations in May 2024. This is reproduced as (WITN7754015). In this briefing, we expressed some of our on-going concerns over failings in the proposed compensation arrangements.
27. After trying to understand the terms of the Compensation Regulations and the unbelievable complex formulae at Regulation 27, we wrote to Nick Thomas-Symonds with our ongoing concerns over aspects of the compensation scheme on 23rd October 2024 (WITN7754016). Our concerns included:
- Lack of information on how tariffs were calculated
 - The inadequacy of the compensation proposed for unethical research
 - Lack of recognition of the impact of treatment with interferon
 - Future operation of the support schemes
 - Failure to make interim payments to those infected with Hepatitis B
 - Issues over individual's ability to identify their date of infection
 - The pressing need for claimants for compensation to have access to independent legal advice.
28. When he finally replied on 4th December (WITN7754017) his office replied to a copy of the letter which had been passed to a local MP who had raised the matter with the Minister. Rather than reply to our letter they sent us a copy of the letter sent to the MP, only they did not remember to attach the copy. We eventually obtained a copy. The letter addressed to Dave Doogan MP was detailed. The letter reflected a general approach of government replaying back to us government decisions without neither answering the questions raised nor giving the rationale for decisions.. On our suggestion that there should be an additional award for those who received interferon treatment for Hepatitis C, the response did not address at all the point that was made i.e. that interferon has in itself a debilitating effect which can be severe during the period of treatment and beyond. On changes to the operation of the support schemes from 1st April 2025, the response played down the significant change that would apply to widows where their partner died after 1st April 2025.

29. There has still not been any announcement on the legal support that will be available to applicants for compensation. We are told this is a matter for the IBCA but they have not consulted on their intentions and made no announcements about how legal support may be delivered and when.
30. On 29th November 2024, we along with the Haemophilia Society, Haemophilia Northern Ireland, The Hepatitis C Trust, Tainted Blood and solicitors BTMK wrote to Sir Brian Langstaff KC as Chair of the Infected Blood Inquiry (WITN7754018). We understand that Haemophilia Wales sent a letter adding their concerns to the issues raise.
31. The letter expressed frustration at the approach taken by government. It cited a lack of engagement and undue influence by the Cabinet Office in the work of the Support Schemes in the processing of claims for interim compensation for the estates of deceased infected, which had caused significant trauma and upset for bereaved families. Additionally we commented that the legal support provided to estates for the purpose of obtaining grant of probate/letters of administration (confirmation in Scotland) was inadequate. Repeated concerns over some aspects of the compensation scheme continued to be ignored.
32. On 5th/6th December the Cabinet Office issued what they termed a “targeted” engagement on the criterion to be applied for those seeking an additional autonomy award under the supplemental route for unethical research (WITN7754019). This was another example of an unreasonable timescale within which voluntary bodies were asked to respond to consultation. We were given just 14 days to respond, during which time we had to consult with our members. We responded to the consultation via the Infected Blood Inquiry Response Team on 19th December 2024 (the closing date for responses) (WITN7754020) drawing attention to flaws in the rationale being adopted. None of the comments we made apart from the inclusion of the Cardiff Haemophilia Centre within the list of institutions where unethical research was deemed to have taken place were accepted. It is notable that this is the only aspect of the supplementary route on which the government has engaged.

33. The Cabinet Office subsequently issued a paper “Update on Unethical Research Awards” on 29th January 2025 providing details of the response to consultation and the government’s rationale for rejecting all but a few of the amendments to the criterion adopted (WITN7754021). This was probably the first time that the government published a response to consultation and its consideration of the responses received. Whilst maintaining that it was only cases referenced in the Inquiry Report that would be considered, the government used additional evidence to justify inclusion of some locations as centres where unethical research was undertaken. The relevant dates that would be considered remained unchanged from the original suggestions, despite information being submitted that showed unethical research being undertaken outside the prescribed dates of 1974 – 1984. Our belief is that any unethical research should be eligible for an additional autonomy award and that this should have formed part of the consultation, not just the two limited aspects on which views were invited.
34. Haemophilia Scotland was invited by e-mail of 3rd December 2024 to send one representative to a meeting with the Minister for the Cabinet Office, Nick Thomas-Symonds MP, on 11th December along with 30 other organisations split across 5 groups, with each group session lasting only 45 minutes (WITN7754022). This was the first opportunity to speak directly with the Minister since his appointment in July 2024. In reality each representative had only about 5 minutes to make any points they wished to raise. We regard this lack of direct engagement for so long on such an important issue as appalling. To expect each representative to speak for only five minutes is an unbelievable affront to the people we represent.
35. From the meeting group the haemophilia organisations were in we had the chance to raise the following issues:
- The time allocated for the meeting (45 minutes) was insufficient.
 - There was an urgent need for engagement on the second set of compensation regulations.
 - More details were required on what independent legal support would be available to applicants.

- Clarification was required on the evidence to be provided to pursue a claim, specifically in relation to date of infection.
- Support Schemes access for widows and those with Hep B going forward.
- Costs of operation of IBCA and need to curtail this and speed up processing to save estimated £100M - £175M over 5 -7 years.
- Those with Hep B and transfusion patients - lack of support to date and problems over evidence.
- The lack of progress on funding of advocacy for organisations named in recommendation 10 of the Inquiry report. The Minister said we would ask his officials to write to the Department of Health and Social Care (DHSC) about this. This troubled us as the DHSC has no remit in Scotland or the devolved nations.

36. In general, we did not receive any answers or meaningful comment on these areas of concern at the meeting or subsequently.

37. As a follow up to the joint letter of 29th November (see para 30), Haemophilia Scotland wrote to Sir Brian Langstaff on 16th December 2024 drawing attention to the unsatisfactory nature of the recent meeting with the Minister for the Cabinet Office (WITN7754023).

38. On 17th December the UK government published its response to the Infected Blood Inquiry (RLIT0002471) . I would comment that almost 7 months from publication of the Inquiry report there remains much work to be done to achieve implementation of the Inquiry's recommendations. I comment further on the government response in reply to question 4.

39. On 20th December 2024 Haemophilia Scotland wrote to the Minister for the Cabinet Office, Nick Thomas-Symonds MP (WITN7754024) drawing attention to our response to the targeted engagement on unethical research and questioning why the government had not published information promised on the full rationale for the tariff based system recommended by the Expert Group. We received a reply on 14th January 2025 from Nick Thomas-Symonds (WITN7754025). On the subject of tariffs,

the Minister suggested that information had been published in August 2024. In our view what had been published were some example figures and not the detail on which the tariffs were based. We remain in the dark as to the basis on which the Expert Group came to the conclusions it did.

40. On 18th January 2025 Haemophilia Scotland and the Scottish Infected Blood Forum jointly hosted a meeting in Glasgow to which the IBCA were invited to attend to update our members and answer questions. Approximately 70 members of both organisations were in attendance. The IBCA were represented by Sir Robert Francis (Interim Chair), David Foley (Interim Chief Executive) and Rachael Forster (Interim Director of Communications). A range of topics were covered with the IBCA undertaking to answer those questions were time prevented a full response. Members found this a useful experience where there was ample opportunity to engage over the two and a half hour session. We made a recording of the event available to those members who were unable to attend. The government could learn from such an inclusive approach rather than limiting representation.
41. Representatives of Haemophilia Scotland, the Haemophilia Society and the Scottish Infected Blood Forum were invited to meet with James Quinault, Director General at the Cabinet Office with responsibility for the Infected Blood Inquiry, along with colleagues. The meeting took place on 20th January 2025 as part of a series of 5 sessions for different organisation groupings with each lasting 60 minutes. Prior to the meeting we raised issue with the Cabinet Office over the lack of pre-meeting discussion on the topics we wished to discuss and a feeling that the meeting would be predominated by our being spoken to, rather than have opportunity to raise our concerns. We were particularly concerned to clarify where the decision making on legal support to applicants lay between the Cabinet Office and the IBCA.
42. During the meeting James Quinault commented on the recent consultation on unethical research stating that the eligible dates for a supplemental claim were to remain as research undertaken between 1974 and 1983, but the institutions to be covered were to include additionally St Thomas' Hospital, London; University Hospital Wales (Cardiff); Manchester Royal Infirmary; and Sheffield Royal

Hallamshire Hospital. This response fell short of the suggestions made in our response to the consultation.

43. On interim payments to estates of deceased infected being processed by the Infected Blood Support Schemes, we were advised that payments had been made in 234 cases, 45 were approved and pending payment, 140 were under consideration and 163 were going through probate procedures. Previous queries regarding the right to pursue an estate claim through a chain of representation had been resolved after considerable upset had been caused to bereaved families who had decisions reversed after having been notified that their application had been accepted.
44. We had opportunity to ask questions and make comment. I provide a summary of the questions and responses from my own notes of the meeting (WITN7754026). The civil servants present were resolute in saying that:
- (a) there would be no change to the payments to be made to widows/partners of those who died after 1st April 2025;
 - (b) that those with Chronic Hepatitis B would not be admitted to the support schemes,
 - (c) there would be no consultation with the infected blood community on the second set of regulations, but there would be opportunity to see an advance summary of the draft content of the regulations and opportunity to attend a briefing on the regulations once they were laid before Parliament.
45. On 29th January 2025 we received what was described as a “readout” of the engagement meetings (WITN7754027). This seemed to cover all the meetings held, as issues not raised in the meeting we attended are included.
46. We also received from the Cabinet Office on 28th January 2025 a Factsheet entitled “Draft Infected Blood Compensation Scheme Regulations Factsheet” setting out what was described as the government’s policy intentions for the Infected Blood Compensation Scheme (WITN7754028). We found that the Factsheet repeated much of what had been said before by government, but confirmed the second set of regulations giving effect to the Compensation Scheme were planned to come into

effect before 31st March 2025. The note provided some additional information on the supplementary route and its interaction with the core route. As an overview of the government's intentions it was helpful, but no substitute for sight of the draft Regulation or consultation on them.

47. At the meeting we were advised that an invitation to a further meeting with the Minister for the Cabinet Office was to be scheduled. That was subsequently confirmed for 30th January 2025. Haemophilia Scotland and other groups we are in regular contact with had reservations about attendance at future meetings as they are being billed as engagement events. These events from our experience are about government telling us what they are doing, allowing minimum time for questions, with generally no answers or rational explanation of the government's plans. This does not equate in our minds to engagement.
48. The meeting with Nick Thomas-Symonds MP, Minister for the Cabinet Office, was held on 30th January 2025 as planned. It followed the same format as the previous meeting and was called specifically to discuss the next set of compensation regulations to be published and laid by government before Parliament. The document referred to at paragraph 46 above formed the basis of the introduction to the regulations made by the Minister. There was then opportunity to ask questions or make comment. On some of the questions replies or clarification was received.

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

49. I have taken the reference to external support and assistance as referring to all manner of support and assistance provided.
50. This has included pro bono support from Thompsons Solicitors and mutual support from other haemophilia charitable organisations. We receive funding from the Scottish government which covers part of our core operating costs which is subject to annual review. The funding has not changed to reflect the additional work we have undertaken in supporting our members in relation to infected blood and the

compensation arrangements. Most of our income comes from grant applications and fundraising. We commit considerable effort to our fundraising activities. Regrettably that has suffered due to the pressure of responding to members' queries and concerns about infected blood and specifically the compensation scheme.

51. We generally enjoy a good relationship with the Scottish government at Ministerial and civil servant level. The Scottish government representatives have met with us and listened to our concerns over the compensation scheme, the future of the Scottish Infected Blood Support Scheme and related matters, but advised that decisions are largely in the hands of the Cabinet Office. Meetings with the Minister for Public Health were held on 27th June 2024 and 16th August 2024. Through these meetings we and the Scottish Infected Blood Forum were invited to join the Scottish government's Oversight and Assurance Group which is tasked with co-ordination and oversight of the Scottish government's response to the recommendations of the Infected Blood Inquiry. The group is chaired by Christine McLaughlin, Director of Population Health, Scottish government. The first meeting was held on 26th June 2024. It is meeting on a regular basis. There has been open discussion in the meetings where the voluntary bodies represented have been able to voice their views in a supportive way.
52. The work we have undertaken in relation to compensation has been to the detriment of our normal activities and has put significant pressure on staff and trustees.
53. It would be remiss of us if we did not acknowledge the massive support that the All Party Parliamentary Group (APPG) on Haemophilia and Infected Blood has been in moving us forward to a stage where the legislative framework is in place for compensation to be paid. Without the tenacity of Dame Diana Johnson MP and Sir Peter Bottomley MP and others within the Group we would not have got as far as we have. Our appreciation and gratitude for their support is appropriately recorded. Since the July General Election the APPG has been re-established with few of its original members. We look forward to working with members of both houses to ensure the APPG continues to be a strong voice in pursuing justice for those infected or affected by the infected blood scandal.

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 Haemophilia Scotland have experienced it.

54. We have sought in our answer to Question1 to give a full account of our involvement with the UK government (Cabinet Office) and IBCA, both of whom inevitably are key players in the process of making compensation payments to the infected and affected a reality. Our reaction to the process we have experienced since the publication of the Infected Blood Inquiry has brought with it a range of emotions, from anger, confusion, disbelief to despair and a belief that the government have not read the Inquiry report, or that despite the many criticisms that have been made of successive governments it feels it is right to ignore the considered comments and recommendations made through the Inquiry process. In many ways we are at a loss to understand the resistance to implementing the recommendations made whilst the government publicly accepts the recommendations, at least in principle for the most part. It is a sad state of affairs where recommendations from a report which has criticised successive governments are not being fully adopted by the current government.
55. Throughout we have found that there was a lack of clarity between the roles of government and the IBCA as a body independent of government. The respective roles became clearer towards the end of 2024, but the staffing of the IBCA by civil servants continued to fire mistrust within the infected blood community .
56. The approach of the UK government, with few exceptions, has been unhelpful throughout. For the infected blood community it has felt that there has been an impenetrable wall preventing the community from engaging and understanding what is to happen to them. We have returned to a paternal “we know what is best for you” approach. We feel in a chicken and egg situation where the Inquiry recommendations on 4(b) (Cultural Change) and 5 (Ending the defensive culture in the civil service and government) need to be implemented before we can move forward.

57. The IBCA has set up arrangements for engagement via a variety of ways with the infected community, but some fundamental aspects of their work have been decided without consultation. I include in this the decision to employ case managers who take applicants through the application and decision making process. The view of many within the infected blood community is that this is a role which would be far better split with the application process supported throughout by independent legal representation, with the IBCA advising on the information they require to make a decision and then taking a decision. Basically there remains a high level of mistrust of government and the IBCA and it is wrong to ask individuals who have been significantly harmed by the state to put their trust entirely in staff employed by the IBCA, without effective legal support.

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

58. Our principal concerns are the failure of the UK government to engage effectively with the infected blood community. Frankly, it feels as though the infected blood community has been completely ignored or deemed irrelevant to the decision making process. Once again we have been disenfranchised, left waiting to see what the government will do next.

59. We seek to express our concerns in making representations, speaking at meetings (where time permits) and writing to MPs with variable response. Our letters are not answered, or they are answered only after a long delay, or they are answered with the government reiterating to us their plans, with no consideration of how things could be done differently.

60. The IBCA have taken a decision to adopt an incremental approach to processing applications. As they say, starting small to test their systems and then progressing to larger volumes. At one level it is appropriate that they get things right, but they are failing to understand the urgency of settling compensation for many who are unwell or of advanced years. It is critically important that these and others who have not

received any interim payments receive a settlement as soon as possible. It is not clear if the IBCA have any system for prioritising categories of applicant. To say they have paid out compensation to 11 out of thousands of claimants is not an achievement to be proud of, however well-meaning and considered they feel there planning and implementation arrangements are.

61. Our members need more certainty about timescales for processing applications for compensation. This will become a much more acute need when the second set of statutory regulations are passed as there will then be a need to process supplementary route applications and consider application from the affected. With many affected and infected of advance years and many of poor health the need for the IBCA to proceed swiftly becomes paramount. It is of little comfort to hear from government Ministers that applications from the affected will start to be processed before the end of 2025.

62. The support schemes continue to work well in making interim payments to the infected and now to the estates of deceased infected. They should be commended for their commitment.

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

63. We are a small charity with just 2 permanent staff and 1 trustee and 1 ex-trustee taking on the bulk of work relating to infected blood. At times it can be all consuming.

64. The support we provide to our members is made more intense due to the lack of a clear message from the government on what they are doing and why. A lot of time is spent explaining to members how the compensation scheme will work when we don't know all the detail ourselves.

65. The government are working to bring into law a second set of compensation regulations by the end of March 2025, but we have been given very limited

information on what the regulations will say and there appears to be no intent to consult on them.

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.

66. Before the UK government announced the details of the Infected Blood Compensation Scheme on 21 May 2024, the lack of transparency and limited updates on progress had already caused significant anxiety and stress within the infected blood community. The government's decision to delay its response to the Inquiry's Second Interim Report until after the final report exacerbated these concerns.
67. Throughout most of 2023, the mood among infected and affected individuals was overwhelmingly negative. Incoming calls to our office and discussions with members were particularly challenging, as no concrete information was available to share, and some members feared that compensation would never materialise. The approval of the amendments to the Victims and Prisoners Bill in December 2023 offered some reassurance, though scepticism remained about whether they would pass into law.
68. In early 2024, uncertainty surrounding the compensation scheme persisted. Tensions heightened after the January announcement of an unnamed Expert Group, which lacked community representation or engagement. Direct interaction with the government only occurred in May 2024, when the Minister for the Cabinet Office, the Rt. Hon. John Glen MP, arranged meetings with patient organisations and campaign groups nationwide. Although these meetings marked an improvement in communication, many in the community felt they were too little, too late, and the secrecy surrounding the government's plans continued to cause stress and harm.
69. The announcement by the Minister for the Cabinet Office, on 21st May 2024 of the terms of the compensation scheme was initially well-received. The appointment of Sir Robert Francis as Interim Chair of the newly formed Infected Blood Compensation Authority raised hopes that the scheme would align with the structure

and methodology outlined in his Compensation Framework and the Inquiry's Second Interim Report. Concerns soon started to be raised over the calculation of tariffs and the future arrangements for support scheme payments.

70. The publication of the "Infected Blood Compensation Authority Proposal Summary" on the Gov.uk website later on the evening of 21st May 2024 caused widespread confusion. The 20-page document, including illustrative examples for categories of awards, raised more questions than answers. Our organisation experienced a sharp increase in calls and emails from concerned members over the weeks following as people were struggling to understand the detail of the proposals.
71. The proposal document was seen to be very confusing, caused the positive feelings from the outcome of the Inquiry final report to be diminished and began to create ill feeling between different cohorts of infection due to the illustrative figures failing to provide information on how they were calculated and raising believe that there was unfairness between the compensation payable to those infected with HIV and those infected with Hepatitis. This period of uncertainty and high volume of concerned enquiries from members persisted for two further months due to the General Election and period of purdah before the new Labour government was formed in July 2024.
72. When the new Labour government took office, the damage caused by the past year was apparent. Many of our members openly expressed a lack of trust in the government's actions and words. The overall sentiment surrounding the compensation scheme was pessimistic, with some members stating that nothing would change and that they were, once again, not being heard. Confusion persisted around the details of the compensation scheme, and there was the widespread fear that the support schemes, indicated by the Scottish government to be lifelong, were at serious risk.
73. When Sir Robert Francis published his report on the findings from the engagement exercise conducted over the election period he made 74 recommendations for changes to the proposed Infected Blood Compensation Scheme. The same day, the new Government released its response, accepting 69 of the 74 recommendations. This was viewed as an encouraging step by the community, demonstrating the

benefits of engaging with the community, addressing their concerns, and taking positive action to improve the proposed scheme.

74. However, this progress stands in stark contrast to the disappointing lack of engagement with the government in the months that followed. The government made no attempts to meet with us. No direct engagement until 11 December 2024, leaving the community without an opportunity to have their concerns heard and providing a breeding ground for reinforcing feelings of distrust and isolation.
75. Throughout the latter half of 2024, many members continued to raise questions, particularly regarding the anticipated launch of the scheme for registration. Concerns centred on what information would be required and how much of their past they would need to recount yet again to another body. Members frequently highlighted the toll this uncertainty was taking on their mental health, with some expressing fears that the scheme might never open.
76. Overall, a lack of transparency, poor communication, and limited engagement with the community have intensified feelings of distrust and isolation. Despite some positive developments, such as the appointment of Sir Robert Francis and the initial response to his recommendations, the broader process has been beset by unnecessary delays, confusing documentation, a lack of engagement and unresolved concerns.
77. The scheme and regulations have raised many questions. The failure of government to respond in a meaningful way to the queries raised by, or on behalf of, members has raised levels of mistrust in the government. The most blatant concern is over the failure of government to communicate in any way with the infected blood community for long periods.
78. It needs to be recognised that many have seen no progress in implementing the compensation scheme since it was announced last May – now at least 8 months ago. Some progress has started to be made on interim payments to estates of deceased infected, but only recently. The focus has been on the alive infected, but even then at the date of this statement only 11 people have received a settlement

payment. The IBCA's target is to invite up to 250 to submit applications by the end of March 2025. It is no surprise that those infected and those affected are dismayed at the lack of progress in implementing the scheme.

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

79. The Inquiry Report foresaw a compensation scheme where those infected and affected were an integral part of the decision making. What we have is something that is as far removed from that concept as it could be. Everything is decided behind closed doors. That has to change.
80. Government need to re-think its approach over the lack of effective engagement with the infected community. Mass meetings with little time to get to the nuts and bolts of the issues of concern to the infected are ineffective and should not be described as engagement. What is required going forward is meetings with individual organisations, or small groups with a shared interest, through which the basis of decision making can be dissected and assessed against the recommendations of the Inquiry.
81. There should be more openness about the policy decisions taken by government and the parameters within which the IBCA operate. There has been a lot of debate about the lack of transparency and the fudging of roles between the Cabinet Office and the IBCA. The relationship and any delegation of functions from the government to the IBCA should be clearly laid out in a public document.
82. One of the issues for us as a small voluntary body is the availability of legal support in understanding the meaning and complexities of legislation. The first set of compensation regulations are complex in part and require understanding of how, for example Ogden tables are used, and how to follow the type of formula contained in regulation 27. We anticipate that the next set of regulations will be more complex and will involve matters such as discussion on evidence requirements, proof of

earning or loss of earnings. Whilst we have been able to call on limited advice from the firm that represented us at the Inquiry, we do not have the resources to fund paid legal support to the level required to help us understand what the IBCA will require. Access to lawyers who have assisted with the Inquiry and who could be funded centrally to provide advice would go some way to putting us on an even keel in understanding what government lawyers are producing.

83. The planned provision of independent legal support to applicants urgently needs review and should be accompanied by a clear statement of available provision from the IBCA. The need for the provision of legal support has been commented on in:

- Sir Robert Francis' Report on "Compensation and redress for the victims of infected blood: recommendations for a framework" ¹
- The Inquiry's Second Interim Report on Compensation ²
- Sir Robert Francis' Report – Recommendations to the government on the proposals for a compensation scheme ³

84. Some clear messages came out from these three reports that:

- Applicants need access to legal support.
- That support should be independent and confidential to the applicant.
- It is vital that funding is sufficient to enable adequate support to be provided.
- Funding to be set within pre-determined fee levels.
- Legal firms associated with the Inquiry are well placed to provide that service.
- Lack of support will provide further distress and anxiety to applicants.

85. The failure to meet fully the legal support needs of applicants is of utmost concern to us. We understand that claims handlers can help with this, but as noted earlier there is a real need to ensure that applicants receive independent legal advice throughout the claims handling process. This is something that has been recognised by the Inquiry and Sir Robert Francis, but as yet has failed to materialise.

¹ 7th June 2022

² 5th August 2023

³ 16th August 2024

86. At present funded legal support is limited to when an applicant signs off their declaration form about their medical condition/history and when they are invited to accept an offer of compensation. In reality legal firms are involved in producing and verifying supporting evidence and assisting the claimant beyond the two stages they are funded for. We believe it is vital that all claimants have access to independent publicly funded legal support throughout their journey through the claims process. Such an arrangement would simplify the role of claims managers employed by the IBCA, bring confidence in the system for claimants and make the process more streamlined.
87. The speed at which claims are settled need to increase dramatically. The IBCA needs to engage about changing the system so that it is seen as fair and equitable to applicants who are not left guided by a claims manager but supported by a legal firm of their choice, engaged and paid for by the IBCA but accountable to the applicant. Such a service should be offered to all applicants.
88. With the secondary legislation due to be passed in March, there is a need for a clear plan of how the affected can be prioritised and processed through the system without impacting on the processing of claims from the infected. As noted, many of the affected (and infected) are of advanced years and in poor health. They deserve to have their claims settled without delay.
89. The UK and devolved governments should move swiftly to implement recommendations 10 (a)(ii) to 10 (a)(iv) on patient advocacy. This would allow the organisation listed at 10(a)(ii) to continue to provide assistance to the infected and affected in support of the early payment of compensation by the IBCA. As yet no one from government has approached the named organisations about this whilst we continue to field questions arising from the lack of clarity over the government's proposals.

Statement of Truth

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

Signed

GRO-C

04/02/2025

Table of exhibits:

Date	Notes/ Description	Exhibit number
20/05/2024	Statement made to the Commons by the Rt Hon Rishi Sunak MP (then Prime Minister)	RLIT0002476
21/05/2024	Statement made to the Commons by the Rt Hon John Glen MP (then Paymaster General)	RLIT0002477
27/05/2024	Letter to John Swinney MP, First Minister for Scotland from Haemophilia Scotland and the Scottish Infected Blood Forum on response to the Infected Blood Inquiry and Compensation	WITN7754002
31/05/2024	Response from John Swinney MP to letter of 27/05/2024 from Haemophilia Scotland and Scottish Infected Blood Forum	WITN7754003
30/05/2024	Joint Letter from Haemophilia Society, Haemophilia Northern Ireland and Haemophilia Scotland to Rt Hon John Glen MP, Paymaster General on funding for advocacy as recommended by the Infected Blood Inquiry.	WITN7754004
03/07/2024	Rt Hon John Glen MP replies to letter of 30/05/2024 referring to work of Sir Robert Francis KC and government commitment to review Inquiry recommendations.	WITN7754005
28/06/2024	Submission by Haemophilia Scotland to Sir Robert Francis KC following engagement	WITN7754006

Date	Notes/ Description	Exhibit number
	meeting raising numerous concerns over the published compensation scheme.	
28/06/2024	E-mail from Infected Blood Compensation Authority Feedback mailbox summarising main themes from engagement meetings in mid-June 2024.	WITN7754007
02/07/2024	E-mail Infected Blood Inquiry Response mailbox providing fuller summary of output from engagement meetings hosted by Sir Robert Francis KC.	WITN7754008
08/07/2024	Letter from Haemophilia Scotland to Rt Hon Nick Thomas-Symonds MP as Minister for the Cabinet Office. Letter describes engagement process with Sir Robert Francis as inadequate and not following the recommendations made by the Inquiry. The Minister is urged to suspend further consideration of secondary legislation until there is direct engagement with relevant campaign and charitable bodies.	WITN7754009
26/07/2024	Letter from Rt Hon Nic Thomas-Symonds MP confirming government intention to deliver justice to the infected community and confirming estates of deceased could apply for interim payments from October 2024.	WITN7754010
02/08/2024	Letter from Haemophilia Scotland to Rt Hon Nick Thomas-Symonds MP about his failure to reply to a letter sent to him and government's failure to engage with the infected blood	WITN7754011

Date	Notes/ Description	Exhibit number
	community.	
02/08/2024	Letter from Haemophilia Scotland to Jenni Minto MSP, Minister for Public Health and Women's Health expressing our concerns as expressed in the letter to Nick Thomas-Symonds.	WITN7754012
19/08/2024	Letter from Jenni Minto MSP, Minister for Public Health and Women's Health confirming actions she had taken to seek to improve the situation.	WITN7754013
15/08/2024	Joint letter from Haemophilia Scotland and Haemophilia Northern Ireland objecting to those organisations being excluded from a meeting where the conclusions of Sir Robert Francis' engagement with the infected blood community was to be announced.	WITN7754014
03/09/2024	Briefing for Members of Parliament on Infected Blood Inquiry and Compensation Scheme as circulated to Scottish MPs.	WITN7754015
23/10/2024	Letter from Haemophilia Scotland to Rt Hon Nick Thomas-Symonds MP, Minister for the Cabinet Office, raising continuing concerns over aspects of the compensation scheme and a lack of promised information.	WITN7754016
04/12/2024	Reply from Nick Thomas-Symonds to Haemophilia Scotland letter of 23/10/2024 enclosing a copy letter to Dave Duggan MP answering the points raised with the Minister.	WITN7754017

Date	Notes/ Description	Exhibit number
29/11/2024	Joint letter from The Haemophilia Society, Haemophilia Scotland, Haemophilia Northern Ireland, the Hepatitis C Trust, Tainted Blood and BTMK, Solicitors to Sir Brian Langstaff KC, as chair of the Infected Blood Inquiry expressing the organisations collective view that the government were in danger of failing the infected blood community, were deviating from the IBI recommendations and not engaging with the community as envisaged by the Inquiry.	WITN7754018
05/12/2024 (amended 06/12/2024)	E-mail to Haemophilia Scotland from IBI Response mailbox extending invitation to comment on two aspects of the government's proposals to pay an additional autonomy award for unethical research.	WITN7754019
19/12/2024	Response to Infected Blood Response Team from Haemophilia Scotland to the consultation on unethical research.	WITN7754020
29/02/2025	Receipt from Cabinet Office an Update on their conclusions from the consultation undertaken in December 2024.	WITN7754021
03/12/2024	Invitation to Haemophilia Scotland and other organisations to meet Rt Hon Nick Thomas-Symonds MP on 11/12/2024.	WITN7754022
16/12/2024	Letter from Haemophilia Scotland to Sir Brian Langstaff KC, Chair to the Infected Blood Inquiry commenting on our concerns over the	WITN7754023

Date	Notes/ Description	Exhibit number
	conduct of the meeting on 11/12/2024 with the Minister.	
17/12/2024	Government Response to the Infected Blood Inquiry Policy Paper	RLIT0002471
20/12/2024	Letter from Haemophilia Scotland to Rt Hon Nick Thomas-Symonds MP on the failure of government to publish a full explanation of how the recommended ranges of awards or formulae for financial and care awards had been calculated.	WITN7754024
14/01/2024	Rt Hon Nick-Thomas-Symonds MP responds to Haemophilia Scotland letter of 20/12/204 without providing the promised information.	WITN7754025
20/01/2024	Summary of questions and answers provided at meeting with James Quinault, Director General Cabinet Office with responsibility for the response to the IBI	WITN7754026
29/01/2025	Summary of discussion at meeting hosted by James Quinault	WITN7754027
27/01/2025	Draft Infected Blood Compensation Scheme Regulations Factsheet received from Cabinet Office on 27/01/2025.	WITN7754028