

Witness Name: The Scottish Infected Blood Forum (SIBF)

Statement No.: WITN7165016

Exhibits: WITN7165017 – WITN7165021

Dated: 11 February 2025

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF THE SCOTTISH INFECTED BLOOD FORUM (“SIBF”)

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

We, Joyce Donnelly and Tommy Leggate, will say as follows:

1. The role of the Scottish Infected Blood Forum, known as SIBF, is set out in our first written statement to the Inquiry (WITN7165001). Our responsibilities as Convener (Joyce Donnelly) and Manager (Tommy Leggate) of the organisation are also as set out in that statement.

Please describe the nature of the work which you and your colleagues within the Scottish Infected Blood Forum, have been undertaking, in relation to the question of compensation, since the publication of the Inquiry’s Report in May 2024.

2. The work has been extensive and varied. It is fully detailed in the supporting table, which lists meetings attended by SIBF and correspondence that SIBF has sent (WITN7165017).

3. Some of the work includes:

- 3 meetings with Paymasters General
- Several meetings with Cabinet Office officials
- Several meetings with IBCA, Sir Robert Francis, David Foley, including Sir Jonathan Montgomery
- 5 meetings with Jenni Minto MSP, Minister for Public Health and Women's Health, where SIBF advocated strongly for chronic Hep B and Post September '91 victims, i.e. *the living excluded infectees* poisoned by the State, to be given access to the Scottish Infected Blood Support Scheme (SIBSS)
- Several meetings with Scottish Government Officials
- Several meetings with MSPs regarding chronic Hep B and post September '91 victims admittance to SIBSS via change to eligibility. Despite representations being made directly to the Scottish Government's Health Minister and the injustice of their exclusion from being eligible for SIBSS, there has been no change to this position, with the Scottish Government taking its lead from the UK Government.
- Several meetings with chronic Hep B victim and post September '91 cut-off victim
- Several meetings with APPG
- Several meetings with Haemophilia Scotland
- Several meetings with Haemophilia Society
- Leading on the 'Getting It Right' document with various charities, organisations and groups (Please see further detail below)
- Preparing a Carer's questionnaire for SIBF members and groups/charities in the rest of the UK
- Weekly Forum meetings, informing and supporting members

4. It is important to highlight that our concerns about the Government's approach began prior to publication of the Inquiry's final report on 20 May 2024. We wrote to Claire Haughey MSP, Convener of the Scottish Parliament's Health, Social Care and Sport Committee, on 24 April 2024, in advance of the Legislative Consent Motion (LCM) being considered for the Victim and Prisoner's Bill,

following UK Government amendments to the Bill. We highlighted very serious concerns over some of the proposed changes which deviate from the recommendations set out by Sir Robert Francis in his Compensation Framework Study and subsequently refined by the Infected Blood Inquiry Chair, Sir Brian Langstaff, in his Second Interim Report. We also highlighted the lack of transparency surrounding the Expert Group that had been appointed to advise the Government about the compensation scheme. We also highlighted the injustice of *excluding living infected victims* from any financial support, or interim compensation, in lieu of full compensation, i.e. chronic Hep B and post September '91 victims (WITN7165018).

5. On 1 May 2024, Clare Haughey MSP Committee wrote to Alex Chalk MP, Lord Chancellor and Secretary of State for Justice in her capacity as Convenor of the Health, Social Care and Sport Committee, highlighting concerns from stakeholders, including SIBF, regarding the content of the UK Government amendments to the Bill, lodged on 17 April 2024, and concerns about the lack of transparency surrounding the expert group (WITN7165019).
6. On 13 May 2024, Alex Chalk MP replied to the Health, Social Care and Sport Committee (WITN7165020). We note among his responses he stated "Payments where individuals have not previously been registered will be *most expeditiously* made through the new Infected Blood Compensation Authority".
7. Prior to the publication of the Inquiry's report, SIBF attended a meeting on 10 May 2024 with the then Paymaster General, John Glen. While we felt like we were valiantly listened to at that meeting, ultimately our views were ignored.
8. SIBF was the lead organisation in producing a document, in support of other campaign groups, called "Infected Blood Compensation: Getting it Right". This document sprung out of the widespread frustration in the community of Cabinet Office and IBCA's responses, or lack of. It highlights the deficiencies in engagement with the infected and affected community, and broader issues regarding the compensation scheme. This document was completed in November 2024 (WITN7165021). SIBF secured a meeting with Sir Robert

Francis KC, David Foley, Rachel Forster and others at IBCA on 18 December 2024 to discuss the document. Also in attendance were co-signatories of the document, being representatives from the Contaminated Blood Campaign, the Hep C Trust, an independent campaigner and two additional SIBF members, including a campaigner for Carers. The key areas highlighted in the document and discussed at the meeting relate to the persistent key aspects of the compensation scheme and IBCA which are at odds with the Inquiry recommendations and community expectations, including: IBCA being judge-led; being a true arms-length body accountable to Parliament; having two expert panels to support the Chair with the immediate task of resolving the errors emanating from the Cabinet Office so-called Expert Group; urgently initiating a formal programme of meaningful community engagement through a victim/patient expert group; holding a full Parliamentary debate on the Infected Blood Inquiry Final Report; and belatedly publishing the Government response to the original Compensation Framework Study by Sir Robert Francis KC.

9. At a recent meeting on 30 January 2025 with Nick Thomas-Symonds MP, Minister for the Cabinet Office and Paymaster General, we sought to highlight our concerns about the delays to payments being made to those who are affected. We have requested he use his power to allow affected bereaved partners' compensation to go to their estates should they die before receiving compensation in their own right, due to the length of time it is going to take for their claims to be determined by the IBCA. We see this as common-sense natural justice given the unprecedented and unique nature of this disaster for thousands of people. For the change not to be made would be a further injustice on those widows, widowers and partners, who have already lived with death for decades, and who are themselves dying at accelerated rates due to old age, infirmity and illness.
10. The work undertaken has been extensive, time-pressured and stressful for all involved at SIBF. The inadequacies of the UK Government's response is woeful but sadly not unpredictable. SIBF staff, trustees and volunteers have genuinely had to 'work at pace', with no funding, to ensure fair representation against what

we perceive as a tide of obstructionist manoeuvres by a Government, and its officials, that is being less than transparent with victims.

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

11. SIBF receives support from Thompsons Solicitors who are available to the trustees and manager to discuss issues pertinent to infected blood and related issues. Much of this legal assistance is not funded and is provided pro bono. The charity receives no other external support or assistance.
12. The charity is not currently funded by any grants and operates solely on the goodwill of its trustees, staff and volunteer members. The volume of work arising after the Inquiry final report has increased exponentially at the same time when there was no funding. This has caused, and is continuing to cause, considerable stress on the charity, its staff and volunteers. What amounts to a full-time post, is being carried out by our Manager, who already has full-time work and job commitments. He undertakes work in his spare time, in lunch breaks, in evenings and at the weekend, and takes annual leave and unpaid leave to attend meetings on behalf of SIBF during a working day. This is understandably untenable.

Please describe the involvement of people infected and affected in the decision-making regarding compensation (whether by Government or IBCA or both) as you and your colleagues within the Scottish Infected Blood Forum have experienced it.

13. SIBF does not believe that its input has been considered in the decision making processes of UK Government. We do believe IBCA have considered some of our various representations.
14. SIBF's Manager attended meetings with the Paymaster General and his Cabinet Office officials, including the Director General of the Cabinet Office, James Quinault, and his deputy, Robin Healey. Our Manager did not consider

the arrangements around these meetings provided substantive or meaningful engagement, but merely lip-service and to rubber stamp an engagement process taking place. The appearance of being listened to was there but it transpired that the decision-making process had already been completed by Cabinet Office; we considered the meetings to be only a listening exercise by Government to allow them to tick a box and appear to engage substantively with the infected and affected community representatives. We perceive senior Cabinet Office Officials to exert substantial influence over Paymaster Generals. We perceive the Cabinet Office culture has changed little from the 1970's. We perceive candour and transparency to be at odds with that culture.

15. The meetings were declared at short notice. The initial meeting with the Labour Paymaster General was abysmal: representatives were strictly allowed only 4 or 5 minutes to address many specific questions that officials directed/restricted our attention to. In our view the meeting was woefully deficient and all participants from other charities and groups expressed the same discontent.
16. The second meeting with the Paymaster General around the second set of regulations was less prohibitive but by then the draft regulations were already well established and appeared to be cast in stone; again, our Manager felt that participation at this meeting was a tick-box exercise for Government.
17. There was no scope for engagement with Cabinet Office Officials before these meetings that could in any meaningful way have impacted on the UK Government's decision-making process.
18. Meetings with Government and Cabinet Office are strictly controlled and managed by them.
19. Our experience with IBCA's engagement is substantively better than this. There have been several occasions where there were protracted lags in email communications, and we feel that was in part due to capacity issues within the organisation as it continued its fledgling existence. These communication issues have dissolved over time and our Manager has had some favourable

exchanges with IBCA directors, as well as its Chair and Chief Executive, where we felt we were being listened to and positively engaged with. However, IBCA's hands are tied by its remit from Cabinet Office and decision-making with them is limited to operational matters of the compensation scheme, which has been designed and managed by Cabinet Office officials. To that extent it is not a true Arms-Length Body in the spirit of the Inquiry's report.

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

20. We are concerned that the involvement of infected and affected people in the decision-making processes of Government is seen as a token but necessary burden on Cabinet Office Officials and Government. One that has to be endured by them to 'tick a box' to show they have truly engaged with victims, listened to them and put their experience front and centre in everything they do. It is very concerning that Government continues to act and exhibit the same themes of lip service for the infected and affected communities across Scotland and the UK. They seem to engineer their policies and decisions in advance and then engineer managed and controlled consultation processes to back-up their already drafted conclusions.

In summary, there is:

- Tacit engagement promulgated as meaningful engagement.
- Insufficient notice for meetings given by Cabinet Office.
- Limited/restricted time of meetings
- Restricted agendas for discussion at those meetings
- A lack of transparency, and
- No meaningful updates

Please describe the impact upon you and your colleagues within the Scottish Infected Blood Forum of the matters set out in 1-4 above.

21. In a word, despondency. In our experience, the whole process has been set-up to limit the availability of the knowledge-holders of this disaster to impact in any meaningful way on the shaping of the regulations, while Government officials' thought processes are still malleable. Instead, we have been invited to engage when decision-making by UK Government has already taken form in the shape of draft regulations, which for all intents and purposes are set-in-stone.
22. This whole process is incredibly stressful for SIBF's trustees, staff, volunteers and members. This process has exacerbated negative feelings and emotions. It has fuelled corrosive anxiety and distrust, distrust of the abusers (Cabinet Office) who get to decide their reparations while hiding behind the cloak of process and 'arms-length' deceit.
23. The charity has no funding and no capacity and specifically it's Manager is at breaking point with regard to this.

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.

24. The impact is that people feel they are being abused by Government all over again. People feel the abusers i.e. Government, and specifically the Cabinet Office, have substantively been left to decide the remedy for their own historic abuse. This has traumatised the infected and affected community even further. The Government know these people are vulnerable, sick and aging and yet operate their activities in ways that exacerbate peoples' anxiety, mistrust, fear, revulsion, anger and despondency. The 'working at pace' lie that was continually peddled by Ministers has further traumatised people in our community.
25. The information that was produced by the Government about the compensation scheme on 21 May 2024 led to confusion and distress that people's support

scheme payments were going to be stopped. The Government has also recently announced that if an infected person passes away after 31 March 2025, their bereaved partner will not receive support payments. Again, this has caused great upset and anxiety.

26. The community has zero trust in a Government, and especially its Cabinet Office officials, that is only now offering compensation because it was compelled to do so. Ministers might have a genuine impetus to help but we perceive their help is curtailed and diluted, and their actions are neutered by the Government officials in Cabinet Office.

27. Nothing has changed except the appearances of engagement and the re-traumatisation of thousands of ill victims and their ageing families. The decision-making of Government and Cabinet Office in this regard is appalling and reprehensible.

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

28. Charities and advocacy groups should be properly funded NOW. This funding should be BACKDATED to May 2024. Failing to do so facilitates the Government continuing to get 'blood out of a stone'.

29. There should be properly funded and transparent legal assistance given to the infected and affected victims. The contrivances of Government to date in this regard have been appalling. Funded legal assistance should be provided to ensure that legal representatives are able to provide advice on the content of regulations and importantly can be involved in meetings where technical updates are given from Government and/or IBCA.

30. There should be adequate transparency by UK Government, Cabinet Office officials and IBCA. The irony is that the candour they seek to promulgate is

nowhere to be seen since the Inquiry report was published. Indeed, staggeringly, quite the contrary.

31. There has been no meaningful engagement from Government. IBCA's hands are strategically tied by the same bureaucracy which seeks to stymie the voices of the infected and affected in Scotland and the rest of the UK.

32. Ultimately, however, with regard to particular steps or measures to be taken by Government/IBCA, we fear 'that ship has sailed', that the horse has already bolted. The key period for constructive engagement seems to have already passed us by.

Statement of Truth

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

Signed GRO-C Signed GRO-C

Dated Mar 6, 2025 Dated Mar 6, 2025

Table of exhibits:

Date	Notes/ Description	Exhibit number
11 February 2025	Table setting out work undertaken by SIBF	WITN7165017
24 April 2024	Letter from SIBF to Clare Haughey MSP, Convener of Health, Social Care and Sport Committee	WITN7165018
1 May 2024	Letter from Clare Haughey MSP to Alex Chalk MP, Lord Chancellor and Secretary of State for Justice	WITN7165019
13 May 2024	Letter to Clare Haughey MSP from Alex Chalk MP	WITN7165020
November 2024	Infected Blood Compensation: Getting it Right	WITN7165021

NOT RELEVANT