



Sir Brian Langstaff
Chair of the Infected Blood Inquiry
5th Floor
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London
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5th of December 2024

Dear Sir Brian

Haemophilia Wales wrote to the Cabinet office on the 17th of May 2024 following my meeting in Cardiff on the 2nd of May 2024 with John Glen the then Paymaster General and Minister for the Cabinet Office responsible for the Inquiry, where I made the following observation: -

'I do not feel the summary (of the meeting) reflects the key message I made very strongly, that the overarching concern of the community is the Government are not implementing Sir Brian Langstaff's 2nd Interim report on compensation'.

We have written to Nick Thomas-Symonds, the current Paymaster General and Minister for the Cabinet Office on five occasions over the course of the six months since the publication of your final report on the 20th of May 2024. We now write to you raising our continued concerns specifically on, but not limited to, the following:

1. The establishment of an Arm's Length Body compensation scheme: The new Infected Blood Compensation Authority (IBCA) is not an arm's length body (ALB) as per recommendation 14 of your Second Interim Report on Compensation dated 5th of April 2023.

'Inquiry Recommendation 14: I recommend that an Arms Length Body (ALB) should be set up to administer the compensation scheme, with guaranteed independence of judgement, chaired by a judge of High Court or Court of Session status as sole decision maker, transparent in its procedures so far as the law permits and accountable directly to Parliament for the expenditure of public funds and the fulfilment of its terms of reference. Appeals should be to a bespoke independent appeal body with a legal chair which will reconsider the decision of the scheme in any case appealed to it.'

Under part 2 of The Infected Blood Compensation Scheme Regulations 2024, the 'Establishment and Administration of the infected blood compensation scheme', criteria are set out for persons who can occupy the chair which do not take the line of your report. It is clear the Cabinet Office do not want and will not accept independent leadership of the compensation body as you recommend.

'Inquiry Recommendation 14: goes on 'The scheme should have procedures in accordance with the principles set out in this report and in particular which:

- a) have regard to the need of applicants for speed of provision, simplicity of process, accessibility, involvement, proactive support, fairness and efficiency;*
- b) involve potentially eligible persons and their representatives amongst those in a small advisory board, and in the review and improvement of the scheme; and*
- c) permit the hearing of applicants in person.*
- d) should have access to the records held by or on behalf of any previous publicly funded support scheme (subject to any necessary consents by the data subjects), and take into account the reasoning of any appeal from the decisions it takes.'*

At the meeting of the 2nd of May I highlighted the Inquiry's findings regarding the inadequacy of the previous schemes. This point was noted and John Glen assured me that as the new body would be a statutory body the mistakes of the past would not be repeated. Now recommendation 14 of your report has not been adopted I am reminded of the evidence of Nick Fish Administrator of The Skipton Fund, assistant to the CEO of the Macfarlane Trust and Caxton Foundation, given to the Inquiry on the 23rd of March 2021, who when questioned by Jenni Richards KC on the operational issues of Skipton reported that, 'Skipton was an agent for the Department of Health providing services within the scope of resources and only operational issues could be raised with the Department of Health' To our understanding the IBCA is being set up in the exact same way.

- The IBCA will not set the regulations for the new scheme and the Chair will have no say.
- The details and right of appeal under the regulations are/will be decided by the Cabinet Office
- Leadership will not be independent or have a chair with the training required for the task (a Judge)
- Reporting is to Government not Parliament
- Sir Robert Francis advised us at the engagement meeting of the 16th October 2024 that he was given 24 hours' notice to accept the position as Interim Chair of the IBCA. The timetable of the Government's inaction from your first Interim Report dated the 29th July 2022 prior to Sir Roberts appointment on the 21st of May 2024, (nearly 2 years) together with the wasteful duplication of the Inquiry's work with the commissioning of reports by Sir Robert (not implemented) and the 'Expert group' led by Sir Jonathan Montgomery (not made public), are well documented in your Report. As a consequence of Government inaction Sir Robert was not involved in the process, nor able to influence the decisions, which led to the formation of the legislation within the Victims and Prisoners Bill. This task conveniently fell to the Cabinet Office. In effect he had been sidelined. A demonstration that this body, at its inception is a repeat of the schemes of the past could not be more clearly demonstrated.

2. Cabinet Office control: At the inaugural meeting of the IBCA Communications Advisory Panel held on the 27th of November 2024, while no terms of reference were circulated in advance of the meeting, it was made clear that the decision-making process rested with the Cabinet Office. The IBCA's sole function being to administer the scheme after decisions on the regulations, eligibility, status and tariffs, have been made. While it is fair to say the IBCA are issuing regular communications, they are unable to answer any of the key questions being raised by the community until they have been given guidance by the Cabinet Office. Simple questions which independent leadership armed with your report could answer. Questions such as:

- a. The Report by Sir Jonathan Montgomery Chair of the Infected Blood Inquiry Response Expert Group having worked on setting compensation is still not available, only the Terms of Reference of the Group with the names of Cabinet Office officials redacted,
- b. Eligibility on compensation in its entirety has not been advised and no information released as the Cabinet office have not directed the IBCA as to the structure they determine to be appropriate.
- c. Whether or not there will be legal representation as the Cabinet Office have proposed Case Workers appointed by the IBCA are to put forward an 'offer of settlement' to the infected and affected claimant. (see point 5 below)
- d. It is clear from the update meetings I attend with the Policy Lead at Welsh Government and the Manager of the Wales Infected blood support scheme that they are unable to answer the above questions and cannot make any decisions as they advise they are, 'awaiting direction from the Cabinet office'.

3. Estates: The Government have deliberately moved away from recommendation 12 of your Second Interim Report on Compensation dated 5th of April 2023, page 59-60 clarifying your recommendation 12 reads, "*A key part of the scheme that I (and Sir Robert) recommend is that a claim may be made on behalf of the estate of a deceased infected person.*" The approach that is being taken in matters of final compensation is to rely solely upon the claims of the estate executor. As we will not have sight of the Regulations for the Affected until March 2025 it is unclear who exactly will be eligible to make a 'a claim in their own right' as an affected person.

4. The Appeals process: As recommendation 14 of your Second Interim Report on Compensation dated 5th of April 2023 which states. *'The scheme should have procedures in accordance with the principles set out in this report and in particular which:*
- a) have regard to the need of applicants for speed of provision, simplicity of process, accessibility, involvement, proactive support, fairness and efficiency;*
 - b) involve potentially eligible persons and their representatives amongst those in a small advisory board, and in the review and improvement of the scheme; and*
 - c) permit the hearing of applicants in person.*
 - d) should have access to the records held by or on behalf of any previous publicly funded support scheme (subject to any necessary consents by the data subjects), and take into account the reasoning of any appeal from the decisions it takes.'*

The process proposed however is a 1st Tier only appeal which is not an independent appeals panel and is effectively no appeal at all and therefore not fit for purpose. This process has been set up to prevent claimants challenging the outcome of the process and is entirely weighted in favour of the Cabinet Office.

5. Legal representation and funding: We have consistently asked for funding for legal support to be provided by our lawyers who were recognised legal representatives during the Inquiry. This has not been confirmed by the Cabinet Office. The Cabinet Office has agreed to provide Legal funding up to £1200 for an Estate to obtain Probate/Letters of Administration which is only payable if the claim is successful. At a recent meeting with the IBCA our lawyers were told that they would receive reimbursement up to £1200 if, and only if, they agree with the IBCA caseworkers' proposal on compensation. Old habits seemingly die hard and the aggressive approach of the Government, in making 'offers of settlement' applies commercial leverage on applicants through their legal representatives.

I have asked for clarification on legal support at the IBCA Communications Advisory Panel meeting on 27th November and was told by David Foley CEO IBCA that they had a constructive meeting with lawyers generally and specifically on this point. In direct contradiction to this position our lawyers report that this was not a constructive meeting.

6. Lack of engagement: Nick Thomas-Symonds Welsh MP for Torfaen was appointed as Cabinet Office Minister with responsibility for the Inquiry on 8th July 2024. Haemophilia Wales wrote to him on the 29th of July, the 14th of August, the 28th of August, and the 2nd of October requesting a meeting and voiced our concerns on the above points. Haemophilia Wales was excluded from his meeting of the 15th of August 2024 with the Haemophilia Society, the Hepatitis C Trust and other campaigning Groups.

The lack of engagement with Haemophilia Wales was raised at the Welsh Assembly Infected Blood Debate on the 4th of June 2024 and again on the 9th of October 2024. Mark Drakeford subsequently confirmed that he had raised the issue of engagement personally with Nick Thomas-Symonds. We were advised on the 3rd of December, as I was drafting this letter, that a meeting has been convened on the 11th December.

7. Consultation as a substitute for action: On 18th of June 2024, I attended an engagement meeting with Sir Robert Francis and Sir Jonathan Montgomery, Chair of the Cabinet Office Infected Blood Inquiry's Response 'Expert Group', The Expert Group set up by Government 'To inform the design of the scheme'. This report has still not been published. The recommendations, provided in an interim summary by the Cabinet Office, are at odds with the findings of the Inquiry, and when asked how he had arrived at his recommendations he confirmed they were 'based on a small number of case studies'. When you presented your final Report, you said in the covering letter to John Glen that:

'5000 people gave evidence nearly 4000 of whom were infected and/or affected'.

Why therefore would the Infected Blood Inquiry Response Expert Group choose to base recommendations on a small number of cases, and why are further recommendations required when already well considered, and evidence supported recommendations exist in your report?

At my second meeting with Sir Robert Francis on 16th of October he confirmed no further information was available from the Cabinet Office and although Sir Robert Francis kindly offered to come to Wales to meet with our members, as he appears not to have the remit to make decisions and cannot answer any relevant questions Haemophilia Wales and our members declined the invitation.

There is a call from some quarters for more consultation with the community and in the next week Nick Thomas-Symonds is proposing to meet thirty-one groups across the UK. We hope this series of meetings will represent the start of the constructive implementation of your recommendations, and informed responses to the questions that have been put to the Cabinet Office since the publication of your first Interim Report on compensation dated the 29th July 2022.

In conclusion, many of the behaviours that brought about the need for a Public Inquiry remain ingrained in the Government's responses. The following are all evident in the latest interactions:

- Continued delay in facing into the decisions and actions. (Langstaff: 'Overview and Recommendations Vol 1)
- Commercial pressure 'offer of settlement' (see above meeting with lawyers)
- Lack of basic secretarial and administrative skills with no circulated terms of reference. (See inaugural meeting of the IBCA Communications Advisory Panel 27th November 2024).
- Redaction of names of Cabinet Office appointees to meetings (See Infected Blood Inquiry Response Expert Group Terms of Reference Govt website)
- Inaccurate notes of meetings (see below Notes from my meetings of the 2nd May 2024 and replies to Cabinet office 17th May 2024, 18th June my note of meeting to members and reply to Cabinet Office 2nd July 2024.
- All of the above allowing the new 'Line to take' narratives to be constructed to undermine the Infected Blood Inquiry Report and Recommendations.

Sir Keir Stamer announced on the 3rd of Dec 2024, with his appointment of Sir Chris Wormald, a career civil servant from a family of civil servants, as Head of The Civil Service; his *"mission-led"* administration will change the way government serves the country which *"will require nothing less than the complete re-wiring of the British state to deliver bold and ambitious long-term reform"*.

On reading this I was reminded of the meeting myself and Baroness Featherstone attended with Sir Chris to discuss instances where Department of Health Officials (civil servants) provided misleading or inaccurate information to both the public and ministers.

(see my note of the meeting 20th June 2017)

https://www.infectedbloodinquiry.org.uk/sites/default/files/50-100_3/50-100/WITN3988053%20-%20Minutes%20of%20the%20Baroness%20Featherstone%20and%20Lynne%20Kelly%20meeting%20-%2020%20Jun%202017.pdf

If The Prime Minister actually wishes to affect this policy and ensure your Report can be used as a vehicle for change, with candour, transparency and honesty as central planks of public service, he would be hard pressed to imagine a better place to start the task than by placing Sir Chris Wormald in a room with your Report. If he is pressed for time in his new role, Volume 1 'Candour and Transparency' p215-217 and Volume 7 Section 'Lines to Take' page 105 to the close should provide sufficient third-party advice to reflect upon.

Yours sincerely

Lynne Kelly CBE
Chair of Haemophilia Wales

CC Nick Thomas Symonds Paymaster General and Cabinet Office Minister,
The All Party Group on Haemophilia and Contaminated Blood,
The Cross Party Group on Haemophilia and Contaminated Blood,
Welsh Government Health Minister, Policy Lead Welsh Government,
The Haemophilia Society,
Haemophilia Scotland and Haemophilia Northern Ireland,
Factor 8, Tainted Blood and The Hepatitis C Trust

Supporting correspondence

For Your Information Lynne Kelly's notes from meetings with requests for further information to be included in Cabinet Office notes of meetings.

LK Note of John Glen meeting 2nd May 2024

I met with John Glen Paymaster General and Minister with responsibility for the Infected Blood Inquiry this morning in Cardiff. Jayne Bryant Welsh Health Minister for Mental Health, Cabinet Office officials and Government Legal Department Officials were observing. My note of the meeting is below:

John Glen started the meeting with an apology and stated the Govt was committed to providing compensation to the Infected and affected. The Infected Blood Compensation Authority (IBCA) will be set up in June /July on Royal Ascent . By the 20th May a shadow entity will be set up until the chair is appointed, and this may or may not be a High Court Judge, this may/may not happen within 3 months. He is meeting 1 representative from each campaigning group / charity across the UK over the next 10days. The Govt are planning to have a substantive response to Sir Brian's recommendations on compensation soon. Sir Jonathan Montgomery Chair of Government's expert group has been working on setting compensation tariffs since his appointment in January 2024. The community will be involved in the regulations for the new IBCA scheme which will be UK wide. The Infected currently registered with the devolved schemes will be given priority within the compensation process.

Lynne Kelly stated that we are disappointed that the Government are not implementing Sir Brian's and Sir Robert Francis' recommendations. We are very concerned that the Govt will be setting the eligibility criteria, tariffs and appeals there will be no consultation with legal representatives to dispute claims, so effectively no appeal. The claims will be decided by a 1st Tier tribunal meaning appeals will be dealt with by people with no Infected blood expertise. There is also concern that the new Arms Length Body (unlike Sir Brian's vision) will not set the regulations for the new scheme and the Chair will have no say in this as the details and right of appeal under the regulations are/will be decided by the Govt. I made the comparison with previous schemes being completely unsatisfactory etc. John Glen said this would not happen as the IBCA will be set in legislation and unlike the past the Govt now accept that compensation and not ex gratia payments will be made

Lynne then asked for a commitment that the ongoing ex gratia payments are for life, but the Minister would only state that the ongoing payments made through existing schemes will not stop, unless replaced. He said he could not give further details on how this would be done ie lump sum / ongoing or any details of the new scheme.

Lynne asked about inclusion of Hep B and Hep C Natural clearers in the scheme, stating that people had been exposed to the virus and should receive compensation. By their exclusion they are not monitored which is very unfair as the virus can lay dormant and could develop lead to problems in the future. John Glen said the Expert Group is advising on this. Lynne made that when the Skipton fund was set up 'natural clearers ' were supposed to be included but the Govt took them out and they were not eligible for payment, the Inquiry witnesses and experts have covered this in their evidence and that is why Sir Brian has included them in his 2nd Interim Report on compensation April 5th 2023

Lynne said we were pleased the Government has committed to providing the £100,000 interim compensation in recognition of previously unrecognised deaths, through the current UK support schemes. John Glen seemed less clear about the interim compensation payment being made through WIBSS and the devolved schemes. Lynne stated how important it is that this group receive the interim £100,000 compensation ahead of the IBCA being established. They have had

no previous recognition or interim compensation for the death of their child, father, mother, brother. The Infected and bereaved partners received an interim compensation payment under Sir Brian Langstaff's 1st Interim Report on compensation in July 2022. I gave John Glen and Jayne Bryant a list of 28 previously unrecognised deaths who are in the 'previously unrecognised death' category.

I also provided consent from families concerned to share their contact details with UK Government and Welsh Government, to ensure the interim compensation payment is made quickly through the existing schemes, as John Glen and Earl Howe had already committed in the House of Commons and in the Lords.

The Minister was heading to Birmingham this afternoon and then Northern Ireland tonight for further meetings with a representative from campaigning groups and charities across the UK.

Lynne Kelly Chair of Haemophilia Wales

On Fri, 17 May 2024 at 09:13, Haemophilia Wales <info@haemophiliawales.org> wrote:
Dear Stephanie

Thank you for forwarding John Glen's summary of the key points of the meeting.

I do not feel the summary reflects the key message I made very strongly, that the overarching concern of the community is the Government not implementing Sir Brian Langstaff's 2nd Interim report on compensation.

A second key message relating to the interim compensation payment of £100k being made through the existing support schemes, has also been omitted from the final bullet point. I said they should be made quickly through the existing support schemes and this has not been included in the final bullet point.

Please can you forward the following information to John Glen :
Page 60 of Sir Brian Langstaff's 2nd Interim Report relating to Further Interim Payments to 'alleviate immediate suffering' and this is why I brought the list of 28 eligible people in this category.

Sir Brian Langstaff 'Accordingly, I recommend that an interim payment of £100,000 should be paid to recognise the deaths of people to date unrecognised and thereby alleviate immediate suffering. This should be done as follows:

- a) where someone infected died as a child or died as an adult without a partner or child, the interim payment should be made to their bereaved parents (split equally if separated);
- b) where someone infected has died and there is no bereaved partner but there is a bereaved child or children (including any adopted child, the interim payment should be paid to the child or children (split equally); and
- c) where someone infected has died and there is no bereaved partner nor child nor parent but there is a bereaved full sibling or siblings, the interim payment should be paid to the sibling or siblings (split equally).

These interim payments should be capable of being made through the support schemes after registration and of being achieved reasonably quickly. They can and should be achievable before the compensation scheme itself is operational'

Sir Brian Langstaff's 2nd Interim Report on compensation 5th April 2023

<https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-04/Infected%20Blood%20Inquiry%20Second%20Interim%20Report.pdf>

I would be grateful if you could forward my comments to the Minister and include them in the summary of the meeting.

I also attach my note of our meeting 2nd May 2024

Yours sincerely

Lynne Kelly

<https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-04/Infected%20Blood%20Inquiry%20Second%20Interim%20Report.pdf>

LK note of meeting and update to Members : Sir Robert Francis KC meeting with representatives from Charities and Campaigning Groups 18th June 2024
on 18/06/2024 19:00

Dear All

I joined the meeting with Sir Robert Francis Interim Chair of the Infected Blood Compensation scheme, David Foley Interim CEO and Sir Jonathan Montgomery Chair of the Government's Expert Group earlier today.

All the points which were fed back to me from everyone in our group were relayed to them, but no new answers were given. All our concerns were also highlighted by the Haemophilia Society, NI and Scotland, Scottish Infected Blood Forum, NI Friends and Families. There was a chat line for anything that we did not cover verbally.

Nothing new was revealed in the meeting by the officials, which was very frustrating and there was a feeling of having to start right at the beginning. I made the point that all the evidence relating to victims is on the Inquiry website but it appears that only a small number of case studies have been used by the Expert Group who designed the scheme. Sir Robert said he wanted to listen to our concerns and that nothing had been agreed yet. I can't think of anything that we did not cover and the atmosphere in the room was one of great disappointment and frustration from all the group representatives. We did not get confirmation about anything new from any of the officials.

Sir Robert did say that any questions on Interim compensation were not within his remit and are being dealt with by Government.

Lucy O'Brien from Watkins and Gunn was on the call in listening mode and Sir Robert has arranged a meeting with legal representatives on 24th June as the Govt have decided to pay legal reps for some preparatory and wash up work for submissions. A note of the meeting will follow from the Cabinet Office.

Regards
Lynne

[Details](#) [Headers](#)

Dear Emma

Thank you for forwarding the high level summary of the meetings with Sir Robert.

I cannot see anything which reflects concerns raised by all the Charities and campaigning groups in the meeting I attended, about Sir Brian Langstaff's 2nd Interim Report on compensation not being implemented. Much distress is being caused to parents who lost children at time, many in this group are elderly and in poor health and this is why Sir Brian Langstaff recommended the interim compensation payment to be made for unrecognised deaths via the existing support schemes (see Page 59-60 of Sir Brian's Report)

<https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-04/Infected%20Blood%20Inquiry%20Second%20Interim%20Report.pdf>

Please can this be point be reflected in the summary

Secondly, under Severity Bandings : Please can the WIBSS enhanced payments for Psychological Impact be included next to the EIBSS SCM. I raised this at the meeting and as only Welsh representative I believe this should be included.

Yours sincerely

Lynne Kelly

On 02/07/2024 11:19, IBIResponse Mailbox wrote:

Dear All

Thank you for attending the engagement sessions with Sir Robert Francis on the government proposal for the Infected Blood Compensation Scheme.

Sir Robert and the team in the Cabinet Office have found the sessions invaluable. Both your verbal and written feedback has been used to inform Sir Robert's report which is due to go to ministers at the end of this week.

As promised, please find attached a high level summary of the themes and issues raised during all four engagement sessions with community representatives.

During the engagements, several of you requested an explanation of the government position regarding the future of the support schemes. As you know, the proposed government scheme will be informed by the engagement led by Sir Robert and your views have been incredibly valuable. The proposed government position in relation to the support schemes can be found on pp18-19 of the policy explainer document that was shared with you in advance of the sessions.

We are also aware some of you raised some questions during the sessions that we were unable to respond to during the meetings. Further detail on these and the support schemes will follow in due course.

We look forward to your continued engagement with Sir Robert and the Infected Blood Compensation Authority.

Many thanks and best wishes

Emma

