Witness Name: Mary Evelyn Grindley
Statement No.WITN2336029
Exhibits: WITN2336030 -WITN2336031
Dated: 1st February 2025

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF MRS MARY GRINDLEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14th January 2025. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Mary Evelyn Grindley, make this statement to the best of my knowledge and belief and will say as follows: -

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

1. My first witness statement to the Inquiry was provided under reference number (WITN2336001). My husband John Wellham Grindley died on 13th June 1994, aged 41, from AIDS, having been infected by contaminated blood products. He was also co-infected with hepatitis C and possibly hepatitis B.

2. I am a longstanding independent campaigner for justice for those infected and affected by contaminated blood. I have been campaigning for 45 years now. I do not belong to any particular campaign group, but I have some association with Haemophilia Wales (although I am not Welsh).

3. My association with Haemophilia Wales began when I met Lynne Kelly at the funeral of the Reverend Tanner, former Chair of the Haemophilia Society. I got to know Lynne Kelly quite well and became close to the Haemophilia Wales group through my representation by Watkins & Gunn Solicitors. Throughout the Infected Blood Inquiry ("the Inquiry"). I attended the hearings with Lynne and the Watkins & Gunn group.

4. I have also attended some of the Welsh Cross Party Group meetings both before and during the Inquiry. In fact, the first time I came to Wales to meet with Lynne Kelly and Michael Imperato from Watkins & Gunn Solicitors was before the Inquiry commenced. I have attended a couple of update meetings in the Senedd building and a number of online meetings after the Covid 19 pandemic commenced.

5. I attend the All-Party Parliamentary Group ("APPG") meetings on Haemophilia and Contaminated Blood. I have been attending these meetings for several years and my attendance has continued throughout the Inquiry.

6. In addition, over the years, I have joined a number of protests outside Parliament. I have also attended Parliament to watch debates about contaminated blood, including watching my MP, Clive Efford, along with other members of Parliament, speaking on behalf of victims in their respective constituencies. Clive Efford MP is now the Chair of the APPG replacing Diana Johnson who has done sterling work for our cause. In the past I have met with Lord Morris, given oral evidence to the Archer Inquiry, attended a meeting with Anne Milton, a former Junior Health Minister, who invited me along with other widows to parliament to discuss our situation but only asked me if I "*had found the House of Commons cafe for a cup of tea*".

I have more recently attended meetings with Jeremy Quinn, the former Paymaster General.

7. Aside from attending Parliament and various meetings, my personal campaigning has taken the form of writing lots of letters. Many of these were used in evidence during the Inquiry. My first statement to the Inquiry (WITN2336001) exhibited a number of these letters which were used during the public hearings. In my campaign for justice for victims of contaminated blood, I sent letters to several Prime Ministers, many Health Ministers, Department of Health, Cabinet Office, the Paymaster General, and a number of different members of Parliament.

8. Over the years, much of my letter writing has been on behalf of people who had been widowed because their partners had died from infection with AIDS or hepatitis C. Years ago when Martin Harvey was the new Chief Executive Officer of the McFarlane Trust, he refused to provide financial support to widows/widowers.

9. It still bothers me immensely that I tried extremely hard but was unable to persuade him to understand that it was not just widows with children and those with disabilities who required financial support as were the rules then. It was all widows.

10. I met with Mr Harvey thinking that he might be sympathetic to what had happened to my husband and consequentially to me. He listened but he didn't really seem to understand or care at all. It was particularly frustrating when he asked what my husband had done for a living. I told him that my husband had been an electronics engineer. He responded by asking whether or not there was some kind of union or society that could provide financial help to me. I was devastated and very angry that he had not understood the situation and that he thought I was only there for myself but I was there for all widows.

11. It was a long time until regular payments were issued to widows and when they were issued, they were means tested. This precluded a lot of people. I

recall that the support scheme wanted access to all my financial information (as I remember it a very detailed form) and I refused to be means tested on principle. It made me feel degraded even more than I already did.

12. The first time I received financial support was about around 3 years ago. This was except for 4 years when my son was still at school. I did receive a burial grant from the MacFarlane Trust. My husband received the first ex-gratia payment and I received the subsequent ones. It was only when the schemes dispensed with means testing that I felt able to apply. Only then was I able to pay off my mortgage (which I only managed to get with the help of Susan Daniels, Independent Advisor to the MacFarlane Trust) and feel financially stable after being left with little support and with a teenage son to bring up after a breakdown whilst trying to work after my husband died. Whilst the schemes are much better now than they were in the past, widows and widowers of infected blood victims are still being treated as if they are not important and they are not being listened to in the establishment of the Infected Blood Compensation Authority.

13. Another matter on which I have campaigned relates to the use of synthetic Factor 8 products. I wrote letters to MPs and my MEP at the time about this issue and even had a question put to the European Parliament in the early 2000s about synthetic blood. The issue at the time was that human blood was not taxed but synthetic blood products were taxed, and this was the reason why Haemophilia Centres weren't bringing synthetic products into the UK for use because of cost and using still human blood products which were potentially still dangerous. Eventually, synthetic blood and synthetic Factor 8 was introduced for children and then to adults as well.

14. As a solo campaigner, I would attend update meetings with the Haemophilia Society, Haemophilia Wales and Watkins & Gunn. However, since the end of the Inquiry hearings in May 2024, whilst I still received update letters from Watkins & Gunn, our solicitors have not been able to meet with us as frequently as during the Inquiry.

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

15. As an independent campaigner, I campaign on my own and I don't use social media, so I rely on the information I receive from IBCA, from conversations with other members of the community and with my association with Lynne Kelly and Haemophilia Wales, along with my solicitors Watkins & Gunn.

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

16. Back in May 2024 when we attended the final hearing of the Inquiry, myself along with all of the other campaigners felt on a great high and it was a triumphant day. I felt we were vindicated at last. In particular, when Sir Brian Langstaff said that it was no accident, and received a standing ovation, this was a pivotal moment for myself and other campaigners. We had worked for years to hear this said in public. I remain extremely grateful to Sir Brian Langstaff, Jenny Richards KC and their team, along with all the witnesses that came forward to the Inquiry. Everybody involved with the Inquiry worked so hard for the duration of the Inquiry. I feel that this was a magnificent effort.

17. On that day back in May, it never occurred to me that almost many months later, I would still be fighting for justice for victims along with all of the other campaigners.

18. The day after the compensation framework was announced at the May 2024 hearing, I attended the APPG meeting at Parliament. About 10 minutes into the APPG meeting, we were thinking and talking about how to proceed with the establishment of the compensation scheme. Just then, the general election was announced. We tried to proceed with the meeting, but an MP came rushing in to announce the election. The meeting couldn't go much

further. We were gathered together with the MPs around somebody's iPad to hear the announcement from Rishi Sunak that he made in the rain.

19. At this time Dianna Johnson MP was chairing the meeting and the other MPs at the meeting had to leave to deal with parliamentary affairs. I remember feeling disappointed that after the previous day's celebrations, we were now struggling once again to have the full attention of those MPs responsible for the implementation of Sir Brian Langstaff's recommendations.

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

20. My understanding of the engagement with the infected blood community is that it has been very little and where it has taken place the meetings have been short and only the main campaign groups have been invited. Even some of the larger and more long-standing campaign groups have had difficulty being included. This indicates to me that the government are only doing lip service to engagement, and it is a tick box exercise, so they are seen to be doing something. In reality, they are making the decisions behind closed doors, and it was said at the last APPG meeting on 17th December 2024 that "*they perceive us as the enemy, not really wanting a partnership with the community to try to resolve issues*".

21. This attitude has arisen because of the lack of proper engagement and lack of progress which has resulted in the IBCA more or less "*slamming the door on victims*".

22. The key issue and source of frustration for victims and campaigners has been the fact that whilst the Government claimed to have adopted the recommendations of the inquiry, they have not done this in reality, but instead carried out steps contrary to the recommendations.

23. An example of this is that the Inquiry recommended that the Infected Blood Compensation Scheme be set up as an arm's length body to the Government and Cabinet Office. This is, as a matter of fact, not the case. All of the individuals involved in the Infected Blood Compensation Authority are Cabinet Office staff and Civil Servants. To victims, these are the very same people who are responsible for the cover up of the infected blood scandal over decades and the appalling treatment of victims, evidence of which was heard in abundance by the Inquiry. Victims of contaminated blood should not be dictated to by the Cabinet Office.

24. Another issue causing extreme concern and frustration to victims is the exclusion of our recognised legal representatives from the establishment of the framework for the Infected Blood Compensation Authority. It was Sir Brian's intention and recommendation that lawyers representing victims in England, Scotland, Wales and Northern Ireland would form part of the group responsible for the setting up of the compensation scheme. That did not happen and as a result there have been numerous legal problems with the current scheme. The firm of solicitors appointed to devise the compensation scheme were not involved with the Inquiry and did not have any understanding of the unique facts of infected blood cases. For example, the Hepatitis C severity bandings in the proposed scheme did not reflect the evidence heard by the Inquiry. Those bandings are now subject to a judicial review challenge brought by an infected victim. This confusion and additional stress and anxiety caused to victims could all have been avoided if the recognised legal representatives were consulted (and listened to) in the early stages of the scheme being devised.

25. A few victims have been approached to commence their claims using an IBCA claims manager and not their lawyer. This is extremely problematic. There is an obvious conflict of interest between the Cabinet Office and victims. Claims managers for IBCA are all currently Civil Servants. These individuals should not be investigating applications to the scheme or making decisions as to compensation awards. This is not what Sir Brian anticipated,

nor Sir Robert Francis. Despite the issue being raised on numerous occasions since May 2024, the position remains the same.

26. Staff at IBCA don't seem to have any familiarity with infected blood issues which is causing victims to have to go through the trauma of telling their full stories to their claims manager.

27. It has not been made clear yet whether or not victims will be able to access legal advice during their applications, and lots of applications are already underway.

28. The information being released periodically by the IBCA at the moment is extremely confusing and offers no clarity to victims.

29. To date, the only applications that are being processed are those of the 'Core Infected'. As far as I am aware, there has been no timeline offered for the applications of those parents who have lost children, children who have lost parents, siblings and those with hepatitis B. These groups have never received a penny in compensation and have not received any interim payments.

30. One of the issues I have spent a significant amount of time campaigning on was the treatment of widows by the support schemes. During the Inquiry, widows were successful in obtaining confirmation that their support scheme payments would be 'for life'. I am therefore extremely disappointed that there has been no clarity offered in respect of those whose partners pass away after the support scheme applications close in March 2025. Will they be entitled to 75% of their partners payment (rising with inflation) or will they lose that opportunity?

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

31. After all this time, the position victims have been put in absolutely beggars belief. The IBCA is at the Government's beck and call and has absolutely no independence.

32. When myself and other campaigners have emailed the IBCA to try to clarify issues, such as the Treloar's research issue, the answer we receive is a vague, generic one.

33. The general concern about the IBCA is that it is another front for the Cabinet Office to be able to use to further traumatise and victimise those who have already suffered so immensely. In general, victims are expecting the scheme to operate just like all of the Alliance House schemes and further traumatise them and their families.

34. I believe that the Cabinet Office are not letting IBCA into the secrets of what they are doing and as a result it is not communicated to the community. It has not been explained why the compensation scheme was not set up in the way that Sir Robert Francis and Sir Brian Langstaff recommended and anticipated.

35. I am aware that Lynne Kelly has been at a meeting with the Cabinet Office and Civil Servants last week, still trying to persuade them to listen to the community.

36. One issue is that all engagement as far as I am aware has taken place on the 'Teams' platform which cannot seem to access, although I can use Zoom. Lots of contaminated blood victims cannot access Teams due to their age and inability to use digital meeting platforms.

37. The updates provided by IBCA do not provide clarity or certainty about what progress is being made. I have been emailing IBCA with questions but have received no meaningful response. These emails are exhibited before me (WITN2336030). Generally, I receive an acknowledgement that they will feed the request back to Sir Robert Francis. I don't believe that anyone is

checking these emails. I believe the purpose of such a generic and unhelpful response is to make victims give up trying to obtain clarity or information.

38. As an independent campaigner, I have not been allowed into any meetings with the IBCA and Robert Francis despite trying hard to do so. I have given up, and I feel totally disillusioned. On 14th June 2024 I wrote an email to the IBCA asking to be included in the early meetings, but I received no reply. Lynne Kelly from Haemophilia Wales asked IBCA on my behalf to include me but they refused. On 25th June 2024 I contacted Sir Brian Langstaff via the Inquiry team, and they left a voicemail for IBCA but still no invite arrived. The email correspondence arising from this request is exhibited at (WITN2336031).

39. I wanted to volunteer to help shape the plans for the compensation scheme as we were asked by IBCA to put ourselves forward. I thought I might have something to offer as a widow and a campaigner for widows over the past decade. I was worried and I am still worried about the lack of representation from the widows apart from the women who were sadly infected themselves. However, I never heard anything back from the scheme.

40. Subsequently Lynne Kelly tried to get me an invite to meetings both with IBCA and the Cabinet Office but to no avail. I was not surprised as I understand Lynne was having difficulty herself accessing meetings.

41. I did 'gatecrash' one webinar with Sir Robert Francis and David Foley on Thursday 9th January 2025 which is the only one I have attended. I was only able to attend because a relative sent me the link as she is a member of the Haemophilia Society. Attendees were allowed to send in questions beforehand. I don't know if the relevant person received the question that I sent I in as I was told it was to be sent to the Cabinet Office, but as yet I have had no reply. It has made me feel again like I did in the many years that I spent writing to MPs trying to get justice for contaminated blood victims and just being ignored.

42. The meeting did confirm to me that IBCA cannot do anything for the affected victims until the second set of legislation, and I also learnt that no other cohorts of victims will be paid out at all until the core infected have been paid out. This means that the process could take years.

Please describe the impact you perceive the decision-making regarding compensation (by Government, IBCA or both) to be having on people infected and affected, and why?

43. I am very angry at the way I have been treated, and I am very concerned for the people of the community who are not in campaign groups, whose voices are not being heard. I am particularly concerned about the widows who are not represented by any group and who are confused with the situation, some of whom are in financial difficulties.

44. Engagement meetings with the IBCA have been for the select few. Whilst IBCA did encourage us to share our thoughts with Sir Robert Francis, I felt excluded from giving any real input which has made me very angry after all these years of campaigning.

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

45. I would have felt much better if the recognised legal representatives had been allowed to help with the setting up of the framework for the compensation scheme. If the lawyers had been involved from the outset, who know the victims' stories and all of the different groups that need to be considered, and their particular needs, then the framework could have been established much more quickly.

46. Victims need to have their lawyers starting off their claims for them instead of IBCA claims managers who are civil servants and know nothing about

infected blood. Victims' own lawyers could calculate their damages, and this could get them through the scheme much faster.

47. There appear to be so many issues that the IBCA has not thought about because they did not involve the people who knew the most about infected blood at the point in time when the scheme was established. This lack of foresight means that the support schemes, who are closing registration at the end of March, must carry on going (even though that is expensive) because there is no alternative established yet.

48. Another issue that is important to campaigners is the recovery of some of the money owned by pharmaceutical companies to help alleviate the cost of the compensation scheme. We don't know what, if any, steps the government is taking against pharmaceutical companies following the outcome of the Inquiry, but I suspect there won't be any repercussions for what happened.

49. Communication with the community must be improved and all the IBCA must stop 'picking favourites' when it comes to engagement. Also, their communications must be clearer and more informative. They need to make a strategic plan and stick to it.

50. There needs to be much more engagement especially with people who are not in campaign groups. The government needs to pass the necessary legislation and not hide behind closed doors. They need to actually read the Inquiry's full report because they are asking the community about things already in the report and retraumatising people in the process.

51. The IBCA needs to better inform victims about what is going on. There is still much confusion because of lack of information. In December 2024 I heard about a submission concerning unethical research which I mistakenly thought needed to be done on an individual basis to be sent to IBCA. This related to research done on haemophiliacs at Treloar's College in the late 60s, early 70s, when my husband was there and Head Boy in his last year.

I believe my husband and other haemophiliacs were chosen to go there for research purposes. I did send the submission and received a reply as if they knew nothing about it. I rang them up and I was correct, they did know nothing about it. Whilst I was talking to them, I realised it was the Cabinet Office asking for the submissions on a collective basis from groups. I asked if IBCA needed the information about the submissions and I sent it to them. They should have received this information from the Cabinet Office. The left hand doesn't know what the right hand is doing. The submissions were only allowed to be sent via main campaign groups, so Lynne Kelly sent mine in for me. Most of this information was already in the public domain via the Inquiry Report anyway.

52. Practical things also need addressing and the IBCA needs to help us better prepare for claiming through the scheme by explaining the claims procedure very clearly and letting us know what documentation we need. They need to provide the calculator they promised to roughly calculate our compensation. They need to start to pre-register affected people not already on the schemes so that the process is faster.

53. The IBCA needs to tell us about the appeal system and whether or not legal advice will be funded in the appeals process.

54. They need to tell us about the supplementary route and how we can claim through this procedure. They need to tell us about our position with regard to ongoing legal representation. They need to tell us about the continuation of psychological support which is a huge concern to victims.

55. As a widow I need to know such things as I will, by the look of it, have to make two claims, one for me and one for my husbands' estate. I don't know yet if I will need to go through probate again because I cannot get an answer to that question. I don't know if it will be a face to face or an online meeting with the case manager. I don't know if I will have to provide evidence of my husband's financial loss or my financial loss. I don't know if I need to have a copy of my husbands will. All of these things I, and other widows, really

need to know so we can be ready to make our claims, but at the moment we are in the dark and this is creating a huge amount of stress.

Conclusion

56. When we had the closing event in May last year and the compensation was announced, the community was elated. When Sir Brian announced after 5½ years of hard work by himself and his team, and years of the community's campaigning, that infected blood was no accident, we felt we were finally listened to and our story had been told. We felt vindicated and someway to partial closure, but now, with the lack of engagement and lack of progress, once again the community is on its knees.

57. The mood now is one of anger, frustration, despair, stress, and disbelief again. We have been made to feel like second class citizens once again. We cannot take this anymore. This feeling is exacerbated by the lack of media coverage which is perpetuating the idea that the general public think infected blood is all done and dusted, despite the media being contacted by various campaign groups. Some campaigners suspect that there is a media block on contaminated blood.

58. I personally feel on the verge of another breakdown. I have difficulty sleeping and my brain is constantly whirling around. I try to distract myself from the situation with various activities, but it is impossible not to have the situation in the back of my mind all the time. I am nearly 76 and not in good health so I want to settle my affairs as soon as possible but, at the moment, I do not see the light at the end of the tunnel.

59. I feel that there will be no conclusion or justice any time soon. I am sure I am not alone with this feeling as it has been expressed to me by other members of the community.

60. Lastly, and in conclusion, I feel the Cabinet Office and IBCA needs to engage more with Sir Brian Langstaff to ensure a speedier conclusion to the payment of full compensation to victims of infected blood. I hope this will be

the case in the near future. I have welcomed this opportunity to assist the Inquiry by making this, my second written statement.

Statement of Truth

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

Signed GRO-C

Dated 31/1/25

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**
10/12/24 – 11/12/24	Email correspondence between Mary Grindley and IBCA	WITN2336030
14/6/24 – 22/1/25	Email correspondence between Mary Grindley and Haemophilia Wales and Mary Grindley and the Infected Blood Inquiry	WITN2336031