Witness Name: DENISE
TURTON
Statement No.: WITN1575049
Exhibits: None
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INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF DENISE TURTON

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

I, DENISE TURTON, will say as follows:

Nature of work done in relation to the question of compensation:

1. I have had to fight to be involved since the publication of the report in May 2024. It was not easy. I firstly contacted IBCA explaining that I was willing to help and be involved as I felt that parents that had lost children as children were not being represented by any other group. TB Parents is mainly concerned with adult children who have died.

2. I cannot remember precisely how I managed to get a meeting with Sir Robert Francis and some IBCA staff on or about 7 November 2024. I think it was through Jason Evans, or maybe Collins Solicitors because otherwise I would not have been invited. Lots of other campaign groups and individuals had been invited to meetings since the May of 2024 but parents of young children were not.

3. I wanted to make them aware that there is no recognition of the impact on the rest of the family following the death of a child from AIDS in the early 1990s. Parents were unable to work and families subjected to horrific abuse and stigma on top of their loss.

4. During the meeting, with Sir Robert I explained that I felt that the tariff calculations did not actually reflect the trauma and made the loss of a child's life worth significantly less than the loss of an adult's life. Lee had his childhood and his future taken away and none of this is taken into account because parents do not have a dependency claim. Sir Robert was keen to emphasise that the compensation scheme would pay more than court damages. He that the figures had been put by government lawyers. He also said that it was more than we would have been awarded if Lee had been in a car crash which would be about £10-15k. It is just not comparable to having a child who was experimented on, infected with HIV and HCV, died aged 10 and whose parents had to fight for justice for recognition that it was covered up by government for decades.

5. I tried to explain that the parents had never had a voice and that they and their children had never been recognised by any of the schemes but I felt as though this fell on deaf ears as although he said that he understood there had been no recognition for parents he then said that the scheme should give some remedy for that and that some may say it was inadequate, it was better than nothing.

6. I think that it was at this point that Rachel (who I believe is IBCA comms) said that there would be an estate claim and one for each parent. She said it was very useful to hear concerns and that she would share them with the Cabinet Office as they were doing the next set of regulations.

7. They were unable to say what legal support would be available or when the schemes would be open for affected parents and estates. Sir Robert said that they hadn't yet decided on the order of claims and that the question of priority

would be one for the IBCA Board. They didn't know how many people would bring claims nor how long the process would take.

8. I had no follow up from Sir Robert Francis following the meeting. I feel that they do not want to be involved with the parents or families of children who have died.

9. I have had one other meeting where I stood in for Jason Evans on behalf of Factor 8 for the Paymaster General meeting and I had four minutes speak. I am still excluded from most of the other meetings and was only at the meetings because of it being Factor 8.

10. I speak to other parents who have lost their children, but there's not much we can discuss as we have no say in anything at all. There is no recognition for the impact a death of a child has on the rest of the family and I think that is why IBCA are not involving parents who lost young children. The tariff is very unfair but it has been set and as far as IBCA are concerned that's the end of it. Lee had his childhood and future taken away but none of this is considered nor will it be appropriately recognised.

What external support or assistance has been available?

11. There is no external support or assistance. There is no legal support other than that which is provide free from Collins Solicitors and we do not know what will be available going forward. This is very difficult for everyone involved because we do need help from the beginning and don't want to go through the claims process alone. We want to work with people that we trust and who know our situation.

12. We need legal support and legal representation to help us navigate the compensation process. It is no good saying we can have legal advice when we receive our offer, we need it now. It would be so much easier if our legal

representatives could just do the work for us from the beginning. The case managers need to remember what people have been through with the inquiry and then this. It's re-traumatising to speak to people who know nothing about us or what we have been through.

13. It is very unfair that the government have legal support and we do not. Making sure that the correct information is available for historic estate claims is not as easy as we were told it would be. For example, we do not know what evidence will be acceptable where there are gaps in medical records. The government has all the legal support and advice at taxpayers expense and we have none. That is not a level playing field.

14. In addition to the above, there is still no psychological support for any of us. It was in the interim recommendations but it is still not being implemented. A lot of people need support. There are a lot of parents who are now elderly, and it is not easy for them. They have age-related illnesses such as cancer and dementia and also tech related limitations. We have fought for decades and many, many parents have died and it still feels like we are totally ignored. To me feels like ongoing mental torture and I am finding it very hard.

Involvement of Infected and Affected in decision making re compensation

15. There has been no real involvement from the Infected or Affected in any actual "decision making". The decisions in connection with compensation for those who had lost young children has already been made without input from us or our legal representatives and I cannot see that it will be changed. In fact, we have had no involvement in decision making whatsoever. All the focus has been on engaging with the infected living and widows although I don't believe that they have necessarily had any real influence as again all the decisions had been made.

16. At the IBCA meetings, there is only one member from each organisation that is allowed to attend only get a limited time to speak. I tried to find the right

questions to put forward for others to ask (as I am not invited), and then I do not get the answers that I want or need. Or they are not able to provide and answer and say they have to check with colleagues or ask the Cabinet Office. Many of the groups are to represent those who are infected living, or to represent widows of infected. The questions of the parents of infected children are not getting through not that it would actually make a difference.

Principal concerns in relation to the involvement of infected and affected in decision making regarding compensation.

17. Parents of deceased young children have not been recognised in putting questions forward in any of the groups to IBCA or the government. IBCA meetings are about the living infected or about adults that died, not about the children. There is no legal support to help us do anything to change this or make our voices heard.

Impact of the above issues

18. It has been very stressful and quite overwhelming. We cannot ask any questions and we have not got any answers. There is nothing I can say to the parents who have lost children because it has already been decided. The trust that we had in the government that was built up during the inquiry is completely gone. It has been shattered due to the approach to compensation. We do not trust the government to do anything in our best interest.

19. The newsletters we receive from IBCA are just words. They are designed to sound nice, but they don't say anything. There is nothing of substance in the letters and the problem is that everyone interprets them in a different way. Everyone just takes their own meaning and what they want from the letters. It's all just empty words. I thought the government understood and everything would change, but it hasn't. I shouldn't be surprised.

20. It is also very hard dealing with Colin's dementia and explaining the process several times which happens every time IBCA sends out a newsletter. Some days I think I can't do it anymore. It's an added stress that we didn't need. It's not just me, I know many others feel the same.

21. I particularly feel for elderly parents, many of whom are now in their 70s or 80s and just want their legal representatives to explain everything in a way they trust and can understand. Many of them only know what is going on because Collins send them a letter in the post.

22. With Sir Robert Francis being chair I did think he would take it forward, but I'm not sure now. I did have hope but that has gone and I am just exhausted with it all.

23. IBCA is not an arms lengths body no matter how many times they say it is. It still reports to the Cabinet Office and has to ask what they can and cannot say. We get the same replies to our letters, it's just a different version of '*the line to take*' .

Impact decision making regarding compensation is having on infected and affected

24. It has caused, and continues to cause, a lot of anxiety and stress. It is making people ill, or if they are already ill, it is making them worse. Some of the jargon that IBCA use is difficult for people to understand. There is a lack of understanding of the parents of deceased children. I do not think we should be sent information that is not relevant for us. I think it would make it easier for parents if we are not sent letters relating to the infected living, for example.

25. IBCA have access to records from the Skipton Fund and other support schemes, so they should be able to know who is alive and who is not. My husband Colin, who suffers from Alzheimer's, gets panicked when we receive letters relating to infected living. I have to explain to him that these letters are

not specific for us. We cannot be the only parents in this situation, we are all getting older.

Steps that could be taken to alleviate detrimental impact

26. They should tailor the meetings for different groups. When we are all in one big group asking questions, not all the questions are being answered. In these meetings we should be given more time to ask the questions. If they tailor meetings, maybe they can have pre-prepared answers that offer more clarity and are more updated. They should also and allow legal representatives to attend as they represent many that the campaign groups do not.

27. Following the recent interim compensation payments to estates, IBCA should be able to deal with the estates of children now. It creates an unnecessary complication for us to have to be invited to speak to a case manager when it would be much simpler for our legal representatives to apply on our behalf and collate all the information required and provide it to IBCA. Our solicitors already have all the medical records. If the process was conducted like this, IBCA would not need as many staff and would process claims more efficiently.

28. I would like to think it would help if Sir Brian held further hearings designed to seek answers from IBCA. However, after watching Rishi Sunak giving evidence, I can already predict what would happen in those hearings with excuses, promises and no action.

29. If there are to be additional hearings, Sir Brian should cover the issue of the lack of psychological support. We need psychological support now. It will be too late once we receive the compensation. Zoom meetings are sometimes held by say the Haemophilia Society to offer support, but not everyone wants to discuss their problems on a zoom meeting. In other parts of the UK, they have bespoke support and I cannot see why we still don't have it in England. That's the support we need. The current position is more stressful than it has ever been. It's not

inquiry, we hoped things would change but now I feel we have gone backwards.

30. I want more clarity with dates. It would alleviate a lot of the stress if we had an outline. We are just sitting around and waiting for the invitation email. The start of the compensation for the infected living has been so slow. I do understand that the infected want their money first but we have had nothing. IBCA need to start processing the simple estate claims, and the only way to see what estates are simple is to involve solicitors in the selection process going forward.

31. It would make it so much easier if our solicitors were involved. We would be talking with people we know and trust. People that have been there with us from the beginning. Once we are invited to make the application, we will have a case manager that we don't know. During the interim payment application process, I was talking to a person from IBCA with no empathy. They do not understand how I feel. It felt like they were reading from a script. They should use the case managers for those who do not want legal representation, but we should have a choice on whether we want our solicitors to act on our behalf. We want to deal with people we know and we can talk to, who know us and have all the medical records. Surely it's easier for IBCA to pay our solicitors to undertake the work, rather than recruit and train civil servants.

<u>Statement of Truth</u>

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

Signed GRO-C

Dated 19/02/2025