Witness Name: GRO-B
Statement No.: WITN7758001
Exhibits: None
Dated: 24 February 2025

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2025.

I, GRO-B , will say as follows:

1. I work in a support role and deal with the infected cohort as well as affected mums, dads, siblings and children.

2. There are obviously daily discussions about why it is taking so long and why not deal first with those who have been dealing with this for the longest. They want to know why they are constantly waiting to be told when they will be dealt with, will it be a few months, I don't know the answers when I am asked. I deal with these queries on a daily basis and have been doing so since I started in this role 5 years ago. It has intensified with the Inquiries final report and the announcement of the compensation framework.

3. I am getting calls from people now who have never been involved before, for example one lady when her infected husband died she got on a plane, went to Greece and never came home, she wasn't involved before but no thinks she

should be involved, so I am getting calls now from people like that as well as those who have been involved in campaigning and the Inquiry. The call levels reached a crescendo, dropped off after the Inquiry finished, but I am now taking more calls then I ever have.

4. I am supported by my employer, I have a supervision session once every 6 weeks. Sometimes I take my worries home with me, I didn't want to do that but because I know the kind of lives people are living as I live that life too its difficult not to. I get guidance from my employer and there is counselling and supervision available.

5. In terms of our engagement, we have had meetings with Sir Robert Francis, Rachel Foster and David Foley, we have all had meetings with those people and those on the panel for the NHS psychological offering. I am on a panel for IBCA, so quite heavily involved with it. The problem is nothing suggested to IBCA is listened to by them. There was once instance where I was listened to, Robert Francis did a video chat where he outlined what had happened and the next steps and I suggested that the video was helpful that it saved people from wading through paperwork, so they did listen to that and they have done other videos since. Any other suggestions however they have totally gone the other way on and done their own thing, not listening to the people at all.

6. One meeting I attended along with others and Rachel Foster, David Foley and Sir Robert Francis, they asked me what my thoughts were as a person involved, who would I think they should pay first. I didn't know why they were asking that question but expressed that what I thought was fair to deal with the people who had been dealing with this for the longest period of time, pay them first, why are they paying someone who only knew of their infection 2 years ago when some have been fighting and battling for 40 years or more. They could pay the bulk of the MFT cohort and get them off their books. Generally a lot of the claims will be very similar so would be quicker and easier to get those dealt with first. The response was oh that is a great idea, lets take that offline. That response is why people don't think its an arm's length body, as why do they have to take

it off line and get checked, people then don't believe them and are afraid of exactly what this is.

7. One thing I have found annoying is how IBCA people are saying how they are learning lessons every day, they shouldn't be learning lessons now, the lessons/mistakes of the past made by the McFarlane Trust and Skipton Fund and Alliance House entitles, they have made the mistakes already so they shouldn't be making mistakes now, the jolly ha ha ha lessons learnt attitude has really annoyed a lot of people and upset people. Even last week on a webinar they were telling people they were learning lessons everyday. I am really sorry but this is not the time to be learning lessons, by doing this they are retraumatising very sensitive and traumatised damaged people and the longer this goes on the worse it will get, it will not get better the longer they hang this out. I did wonder if I was being oversensitive, but thought no, this is a mickey take, I think the crux of it is, they haven't actually been given all of the funds yet, the government haven't just handed them £11.9 billion and said get on with it. I understand they have only paid about 7 claims out of 65 or so who have been invited to claim, that is not a great hit rate for anything.

8. IBCA have a social media presence but they don't answer any of the questions the community ask them on those platforms, have suggested that once a week they go through the questions and provide a response to the ones they can respond to.

9. In terms of the user trustees that IBCA have employed two of them one hates the other one so not sure how that is going to work and I discussed this with Rachel Forster at the beginning. I am concerned that the 4 people appointed do not know anything about living with haemophilia coinfection and whether they are making or asking for decisions to be made for the whole community when they don't live that life that we live, that is a massive major concern. Another big concern is about people commenting about how difficult it is to live with Hepatitis C and saying it is a lot worse than HIV, it plainly isn't especially if living with a coinfection. I think IBCA are trying to involve enough people across the spectrum of the community, they are having meetings with everyone and

their dog, but they are just paying lip service and not willing to take on board anything we have been trying to get across to them, they are just not interested. They never follow anything back up, we asked a number of questions at the meetings we had with them in October and we are still waiting for them to contact us with a response.

10. To me, what Sir Brian Langstaff envisages and what Sir Robert Francis envisaged is a facsimile of it. Many in the community complained because they wanted to keep their monthly payments and have a lump sum and they have got what they asked for and are now complaining about it. In my own view EIBSS could have dealt with the McFarlane Trust Cohort, they have done the grants and payments and interims why couldn't they deal with the lump sums?

11. IBCA are spending a lot of money on case managers, they seem to have spent a lot of money for very little movement forwards so would question where the money has gone. What they have done is make an easy job hard, that's what they are doing, they could have dealt with the McFarlane Trust cohort straight away, all of the clams are very similar, we were all affected around the same time and are now into our mid 50s, most of us are in that age bracket, there will be a little give and take but a lot of the claims will be virtually the same.

12. There has been a massive impact on people's mental health, it is off the scale, EIBBS will be swamped with people's mental health anxiety. People I have spoken to have talked about being in a dark place, feeling listless and upset. Two lads I have spoken too have cried on the phone and dealing with that upsets me as what can I do? People started to make plans when the compensation scheme was announced and now their plans are on hold because it is taking so long, people want to be able to start thinking about moving house, buying a car, getting a mortgage or making new investments, everyone wants something different. People are telling me they are upset and nervous and checking social media daily and even hourly for news. Anxiety levels are rocketing to levels people have not experienced before, people are crying, unable to function, unable to eat, feel sick, feelings of loss, trauma and being retraumatised, a number of people have said to me they have been

getting pruritus', urticaria, itching and welts under the skin, people are in fight or flight mode. Physical wellbeing is low, people are at a low ebb feeling that all the hard work they have done campaigning has been for nothing. At one meeting one kid said "we won that inquiry, Sir Brian said it was not a mistake, it was not an accident which we had been told all our lives, and what have they done is put the people that hurt us in charge of the money. Don't let anyone kid you its arm's length" and that has been the general feeling amongst the people I have been supporting.

13. There has of course been an impact on me dealing with all of this. I am concerned for my mental health. My fiancé is, like myself a core participant, she lost her dad. She is very centred and sensible and if I get wound up and cross she tells me to stop and breath. Our relationship is not straightforward, she works away and I am here on my own, we have zoom calls each day but I feel isolated and worried, I am losing weight more rapidly than I would like, I cant be bothered cooking. We were making plans to move house, but all of that has had to come to a grinding halt again after being told this will be sorted out, its like a carrot being dangled. I don't feel suicidal or anything like that but I am really brassed off with it all and being disrespected being told one thing is happening then it does not, that's not true and being lied to.

14. At one meeting I attended, a webinar the Haemophilia Society did last week we came away from that knowing less than when we joined it. IBCA were involved with it and were saying they are setting up a legal panel so they can use one of the firms for support, we can use their legal support and people were like, what can't we use Collins, the law firm we have been using and the response was yes you can use them – it was confusing the way the information was put across to us. They should think about how they present the information.

15. Steps or measures that they could take, firstly IBCA should be transparent and they are just not. Secondly they and everyone connected should proof read everything they send out, people go crazy as soon as an email is sent out, people are hanging on every word. EIBSS sent an email/letter last week about the schemes closing on 31st March, but if already signed up disregard the letter

– there seemed to be no point to it, raised peoples hopes at having a communication from them then it was something we all knew anyway.

16. We were promised all of our details were being shifted over to IBCA and there would be no more paperwork to be filled in when of course there is, we have to find dates and stuff. We have been directing people to Russell Cooke to get their McFarlane records, but that now has had to stop as they have told us they have passed all their alliance house paperwork to IBCA so now people are ringing up IBCA saying their dad has died and needing his MFT number and IBCA are telling them they haven't got it and I am sure that Russell Cooke are not lying when they have said they have sent all the paperwork across to them. Is it any wonder people are losing their minds when told one thing and then another.

17. One thing they could do is set out a proper timetable about which people are getting paid and when, we all want it dealt with so we can move on with life. I have had a terrible time over recent years in my personal life but have now got to where I am in a good place with my new partner and now IBCA are making a massive dent in my mental health.

18. When IBCA communicate with people they need to use language that anyone can understand, so that a child could understand it. A lot of our cohort didn't spend much time in school and parents looked after their every whim because they were over protective, so they do not understand a lot of the communication that comes out, it needs to be set out in very simple language.

19. We were told a calculation would be available, but we are still waiting for that, the McFarlane Trust was set up in around 8 weeks or so and got people paid out quickly. A lot of us don't see ourselves getting paid out this year, I don't think they have the impetus to do it. One friend I am in contact with, he is a coinfected haemophiliac, has had problems with his liver the last couple of years, he is a really nice kid, I really like him, he is in hospital and has been for many months and has said to me he really thinks he will not see the end of this, his liver is packing up and he thinks he will not live to see a payout. People in

end of life care should be paid out first, they have been persecuted and treated like crap for the longest period, pay these people first and get them off their books if they opt to take the full amount rather than ongoing payments and they can start living what they have left of the rest of their lives rather than waiting to be paid out.

20. I have no idea how they are deciding who to invite, I have asked what the criteria is are they pulling numbers out of a scrabble bag or are they using a random number generator and was told they couldn't say as it would prejudice people going forward. I don't see how that would be the case, people would then know when they were likely to be called, not knowing is like being in a waiting room for death. I remember in one meeting with Sir Robert Francis in October 2024 I asked would I still be sat here in October 2025 waiting to be paid and he indicated that all infected people would be paid by April 2025, well clearly with the numbers so far that is not going to be the case.

21. I am lucky that my family's attitude was to get on with life, I didn't sit at home I went out and worked and was resilient, my Dad's attitude was don't sit on your arse, get into work and see it through to the end.

22. I do feel that those involved in IBCA, running it and making the decisions should be called in and questioned by the Inquiry. I understand they have to test run the service, that is fine, but it need to move forward quicker.

23. I don't want this to be a McFarlane Trust Part 2 and it is now heading that way and would hate that to be a moniker albatross around its neck, they won't want that, I have told them on 5 or 6 occasions if they are not careful, they need to get it right from the beginning, they have to get it right first time and if they don't get it right they wont get buy in from everyone and now what, people are being left in the dark given the run around. If people don't have the information they have to find it, people whose relative died 30-40 years ago are being told on the balance of probabilities that's what happened and then told by IBCA that it hasn't – the people dealing with these cases need to be fully trained and they are not. Why didn't they say, have 10 infected and co-infected involved with

the training telling them what to say, its seems to be a slap dash drawn out approach that is being constantly displayed to the community and is doing nothing but harm both for peoples mental, physical and spiritual health, the way this is all being handled is going to cause some people to get very poorly and possibly even commit suicide.

<u>Statement of Truth</u>

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

GRO-B

Signed ____________________________

Dated ______24/2/2025____________________

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**