Witness Names: WITN1387 & Alan Burgess
Statement No.: WITN7752001
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Dated: 23 January 2025

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF WITN1387 & ALAN BURGESS

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

We, WITN1387 and Alan Burgess, will say as follows:

1. We make this statement jointly on behalf of The Birchgrove Group and in response to a Rule 9 Request from the Inquiry, dated 14 January 2025.

Nature of the work which we have undertaken since the publication of the Inquiry's Report in May 2024.

2. On 20 May 2024, along with thousands of other infected and affected victims, we attended the unveiling of the Inquiry's Report at Central Hall, Westminster. We were overjoyed with the Inquiry's findings and Sir Brian's comments; we finally felt vindicated after decades of campaigning – the truth had finally been published.

3. Our joy was short-lived; not because on 21 May 2024 the Government announced that it would compensate victims, but because of the document which they published that same day, titled "Infected Blood Compensation Scheme Proposal Summary" (WITN7552002) [1]. There were three major problems with the document:

    a) We took it as implicit from the document that, contrary to the recommendations of both Sir Robert Francis (in his Compensation Framework Study) and Sir Brian, in his Second Interim Report, regular payments through the Infected Blood Support Schemes ("IBSS") would halt after a person had claimed compensation and would be discounted against a person's compensation entitlement if received after 1 April 2025;

    b) No detail was provided as to what external assistance would be available to Claimants and particularly, no mention was made of the provision of legal advice; and

    c) Whilst acknowledging that the document was a proposal (and therefore might be considered the start of a conversation), it appeared to us as having been prepared without any consultation with infected and affected people whatsoever. Moreover, the proposal appeared to us to deviate from the recommendations of Sir Robert and Sir Brian in a number of ways, which was a cause of significant concern. We felt that Sir Brian's recommendations laid the foundations for a fair and equitable process of paying compensation.

4. On 23 May 2024, the Government held a Teams meeting which was described as a "Government Technical Briefing" on plans for the compensation scheme. We were initially advised that only one member from each campaign organisation would be allowed to attend though after making clear that we would both need to attend in order to have a sufficient note to pass to our

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community, we were both allowed to attend. As we recall matters, lawyers were initially not allowed to attend the meetings (and certainly were not contacted with invitations) though ultimately were allowed to attend in "listening mode" i.e. they were not allowed to speak.

5. The meeting was a shambles with a large number of different factions of the infected and affected community brought together, all attempting to ensure that their cause was furthered. We do not believe that the meeting could possibly have served any useful purpose whatsoever, save that it left us with the clear impression that the Government's proposal document was not the start of a conversation but rather, the Government's statement of intent.

6. The meeting on 23 May also made clear to me beyond any doubt that the Government intended to scrap the support schemes and regular payments. On 24 May 2024, I (WITN1387) contacted Bill Wright in Scotland to ask what he thought would happen to regular payments made to Scottish victims through the SIBSS; Bill was adamant that the Scottish scheme would continue to make regular payments to its infected and affected beneficiaries, irrespective of the Government's intentions.

7. On 27 May 2024, we wrote jointly to Hannah Smallwood and Brian Williams at the Cabinet Office (WITN7552003) [2], our email read:

   "Dear Hannah/ Brian

   Over that last few days we have had time to speak with many individuals and official groups, it is overwhelmingly obvious that the removal of the regular payment schemes cannot be allowed to happen, this was unanimously conveyed to John Glenn at the various meetings which were held with the campaign groups.
   We are hoping that Sir Robert will not try and push through what is essentially going against his own recommendations.

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We also feel we must mention the meeting last week were we had to hear uneducated and derogatory comments about those of us living with co infection, it is for this reason can I suggest that meetings in the future should not contain individuals but our legal teams to act as intermediaries on our behalf, this will allow things to progress without hindrance by those who have personal agendas.

Many thanks
Regards
[WITN1387]
Alan Burgess
Birchgrove Group"

8. Within seven days of the publication of the Inquiry's Report, it had become clear to us that if there was to be meaningful engagement by the Government in relation to the compensation scheme, that engagement should be between the Government and our recognised legal representatives ("RLRs"). We felt this way because:

    a) The structure of a compensation scheme is not something easily understood by a layperson. The correspondence we had received from the Government at that point was indecipherable and we had no clear understanding of what was being proposed.

    b) This general lack of understanding contributed to the chaos at the technical briefing on 23 May; where people cannot completely understand the issues which they are being asked to discuss, they can be reduced to simply arguing for what is in their, and their group's interests.

    c) The people with whom the Cabinet Office and Infected Blood Compensation Authority ("IBCA") have sought to engage are the leaders of the campaign organisations which the Infected Blood Inquiry is familiar with. Many of these people have been involved in campaign work for more than a quarter of a century and had hoped that that work had come to a successful conclusion with the Inquiry's May 2024 Report. Instead, we are now expected to act as a conduit between the Cabinet Office and IBCA on the one hand and the wider infected and affected community on the other. We are expected to do this without any external assistance and in effect, with one arm tied behind our backs; provided with information which is largely unfathomable to a lay person.

d) If the Cabinet Office and IBCA wanted to engage in meaningful discussion and collaboration on the construction of the compensation scheme, then I fail to understand why they would not have sought to engage with our recognised legal representatives. The majority of infected and affected people are represented by the RLRs who supported them through the Inquiry; a relationship of trust has been built with those lawyers and they have a deep understanding of what the infected and affected community want to see from a compensation scheme. It is incomprehensible to us that the RLRs were not the first people contacted by Government in relation to the design of the scheme; not only are the RLRs best placed to understand how the scheme should work, it would also have saved placing an unnecessary burden on tired and ill campaigners.

9. To the best of our recollection, it was in early June 2024 when the Government published a document titled "Infected Blood Compensation Scheme – Engagement Explainer" (WITN7752004)[3] and opened a consultation with the Infected and Affected Community. A cursory look through the document makes clear that the content is unlikely to be accessible to all but the most capable lay people. The methods for calculating financial losses and care costs are incomprehensible.

10. The publication of this document was followed swiftly by a series of engagement meetings with campaign organisations during the week

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commencing 17 June 2024; again, our legal representatives were permitted to attend these meetings but were not allowed to speak. On 24 June 2024, a separate meeting took place between the Cabinet Office/IBCA and the RLRs.

11. The ‘explainer’ document referred to above confirmed beyond any doubt, the Government’s intention to do away with the support schemes (see pages 18-19) and to the best of our recollection the vast majority of our engagement meeting was taken up in attempting to explain to the Cabinet Office and IBCA why this was (a) something that the community could not tolerate; (b) a source of enormous anxiety and distress to the community; and (c) contrary to the recommendations of both Sir Robert and Sir Brian in their respective reports.

12. As we recall the meeting, the Cabinet Office and IBCA tried to assuage concerns about the removal of the support payments by referring to the ‘top-up’ payment which would be made. The top-up payment was (as we understand it) essentially designed to act as a guarantee that no person’s compensation payment would be less than the amount they would have received through the relevant IBSS over the remainder of their life. In our opinion the design of this ‘safeguard’ top-up payment was fundamentally flawed because it failed to recognise that IBSS payments were only intended to be discounted from forward looking financial loss and care calculations. The operation of the safeguard as proposed would have the effect of crediting a person’s IBSS payments against all heads of their compensation award.

13. At the meeting between the Cabinet Office, IBCA and RLRs on 24 June 2024, we were told that this very point was raised by our solicitor with Sir Robert Francis; Our solicitor’s understanding of Sir Robert’s response was that there had been a misunderstanding and that a Claimant would be able to take their Injury Impact, Social Impact, Autonomy, and historic loss and care awards and then forward looking loss and care awards would be calculated in line with the scheme proposals and, if less than IBSS payments, would be topped up to that amount.

14. The collective effect of this round of engagement meetings was that more questions were asked than answered and written submissions were invited by no later than 28 June 2024. We were both unable to prepare a submission but one was prepared by Milners Solicitors (WITN7552005) [4] which we agreed with entirely.

15. The four day gap between the IBCA's meeting with RLRs and the deadline for submissions was too short to enable Milners' submission to be made with the full input of everyone they represent, but it is illustrative of the fact that the RLRs have a deep understanding of what the infected and affected community want from the scheme, that their submission covered every key point that we would have addressed, comprehensively.

16. On 14 August 2024, Sir Robert published a report (WITN7552006) [5] on the compensation scheme proposals, themselves published on 21 May 2024; this report was prepared with the benefit of submissions made by campaign organisations, individuals and RLRs; the report contained 74 recommendations. The most important recommendations to us were (i) that the support schemes would remain open to anyone registered with them by 31 March 2025 with support payments thereafter being credited against future financial losses and care costs only; and (ii) that legal support would be provided.

17. The vast majority of Sir Robert's August '24 recommendations were taken up by the Government and the regulations establishing the Infected Blood Compensation Scheme ("IBCS") were laid on 23 August 2024.

18. At this point, we had expected that all of the underlying work on the compensation scheme had been done and that the IBCA was simply waiting for the Regulations in order to begin its work – this was not the case and it

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would take until November 2024 for the first handful of claimants to be invited to make their claims.

19. On 17 October 2024, the IBCA sent an update to infected and affected people confirming that 20 people would be invited to make their compensation claims. The update said that the people selected were chosen because they were registered with a current support scheme, collectively represented all areas of the UK and represented a range of infection and severity types. The update went on to explain that the IBCA had adopted a methodology of starting small to improve and develop the service so that payments could be made sooner and more efficiently to all.

20. The selection criteria for the first 20 claimants seemed to us to be vague and certainly didn't make any suggestion that the neediest were being prioritised; in any event, neither we nor any other coinfected person (insofar as we are aware) was invited to make their claim.

21. On 3 December, we received an invitation to a virtual meeting on 12 December with the Cabinet Office Minister, Nick Thomas-Symonds. We were both busy on 12 December and so made our apologies and asked whether it would be possible to have a meeting the following week. We should note that we also had some reluctance to engage in further virtual meetings which tended to bring together a large number of different campaign organisations leading to the meetings being at best, unproductive.

22. We were offered a face-to-face meeting with Sir Robert and the IBCA's Chief Executive, David Foley, on 8 January, in London.

23. On or around 3 December, we understand that a further 25 infected people were invited to make their claims to the IBCA followed by a further 25 on or around 15 January. Of the 67 claims which have proceeded or are proceeding, we know of only one HIV/HCV coinfected person who has received an invitation.

24. Returning to the meetings which were arranged at the beginning of December, part of their purpose was to discuss how to prioritise the issuing of invitations to make claims for compensation. There are a number of points to be made on this front:

    a) It seems to us a little late to start consulting on (and indeed, beginning to consider) the order of priority in which invitations to claim ought to be made. We can understand that it might have been necessary to gain experience of a full range of infections to begin with but given the methodology which the IBCA had settled upon, we would have expected that they would have had some idea of how they would form criteria for issuing invitations after the first tranche of claimants.

    b) A consultation on this point seems utterly pointless. Every group whom the IBCA consults with will understandably advocate for the prioritisation of that group's area of interest. The IBCA should have developed an objectively fair process of prioritisation in circumstances where they knew that the scheme would not be open to general applications for some time. To our minds, an objectively fair system would take a list of all current infected IBSS registrants, order them from oldest to youngest and start at the top with some mechanism for expediting those with terminal illness and/or co-infection.

    c) It is our understanding that by the end of March 2025, the IBCA's target is to have issued 250 invitations to claim. We are also promised the balance of regulations by the end of March 2025 which will fully empower the IBCA and enable it to begin processing applications from affected people. We appear to be heading toward a situation where, on 1 April, the IBCA will have (if it meets its own target) issued 250 invitations to claim (around 7% of infected IBSS registrants) yet with over 90% of those claims left to process, will presumably begin applications from affected people.

    d) This is not to say that affected people are not also desperately in need of having their claims satisfied, we intend more to point out that whilst the IBCA belatedly attempts to deal with one issue of prioritisation, another one is brewing.

25. Another recent topic of consultation has been how awards for unethical research should be applied to claims; the IBCA's initial proposals had limited the fixed sum awards of £15,000 to former pupils of Treloars and £10,000 to infected people treated at a small number of hospitals between certain date ranges. These proposals are considered inadequate by us and the Birchgrove Group because they fail to recognise (amongst other things) the widespread research which was conducted by Craske and the UKHCDO at Haemophilia Centres throughout the country.

26. Aside from the fixing of our meeting with Sir Robert and Mr Foley, December also saw Sir Brian write to the Cabinet Office about the concerns which had been raised with him over the operation of the IBCA. Sir Robert made a near instant response on 10 December which gave us the following concerns:

    a) Sir Robert sets out that the IBCA is an Arms Length Body ("ALB") as recommended by Sir Brian. He goes on to explain that some concern may have arisen because the staff and board of the IBCA are all civil servants but that this problem will go away when the IBCA is able to employ staff directly. Firstly, the IBCA may fulfil a technical definition of an ALB but staffing it entirely with civil servants seconded from the Cabinet Office and Treasury does not suggest the kind of independence which the infected and affected community had hoped for and expected, nor does it have any regard for Sir Brian's recommendation that the board should not feature a majority of civil servants currently in post.

    b) It is unclear to us why we should expect the current board and staff of the IBCA to act independently of government merely because of the technical change of the name of their employer from, say the Cabinet Office, to the IBCA.

27. Moving into January 2025, our meeting with Sir Robert and Mr Foley took place on 8 January; we found it a deflating experience:

    a) We first asked what the arrangement was with our lawyers and whether we would still be able to have them assist us through our claims; Sir Robert said *"The solicitors are basically being greedy and asking for too much money"*. We knew this to be untrue because firstly, the Cabinet Office has only paid the RLR's £2,200 each for their engagement with the IBCA since May 2024 despite working on the compensation scheme continuously; and secondly, we knew that an interim contract had been agreed with our solicitors which covered the first 17 applications to the IBCA so clearly, some mutually agreeable figure had been reached at some point.

    b) We moved on to discuss the order of priority for claims to be invited and said that there were 1,243 haemophiliacs who were infected with HIV and HCV and why did the survivors of that group not appear to be amongst the first invitations to be made? We were told that Sir Robert had met with other groups who thought that they should be at the front of the queue and that placed the IBCA in a difficult position. We were then told that it could well take 5 years to pay compensation to everyone which left us terrified; many of the infected and particularly co-infected community simply don't have that amount of time to wait. As we noted previously, the only objectively fair way of prioritising claims is to start with the oldest whilst also having regard for the number of infections a person has and/or whether they are terminally ill.

    c) We next discussed the recent employment of User Consultants by the IBCA. Our view is that these are unnecessary positions which will serve only to generate anger and disunity amongst the infected and affected community: we asked what the User Consultants were being consulted upon and Sir Robert was unable to give an answer. The user consultant position bears remarkable resemblance to the user trustee positions that existed within the MFT and we had hoped that the IBCA would do all that it could to avoid comparisons with the Alliance House Organisations. We were left with the impression that the User Consultants had been employed for the mere purpose of adding to the veneer of engagement that the IBCA seeks to create.

d) We noted that insofar as we were aware, none of the user consultants had been directly infected with any infection from contaminated blood products; the response was simply that the positions had been advertised openly and we could have applied for the positions had we wanted to.

e) We then discussed the unethical research additional award and we tried to explain that the limited number of institutions which had been selected was unsatisfactory. We told Sir Robert and Mr Foley that they would be hard pressed to find an infected haemophiliac who didn't consider themselves to have been subjected to unethical research whether that be through the Craske or UKHCDO studies, through the utilisation of American blood products after AIDS became known of or through the use of concentrates when other synthetic or safer alternatives would have sufficed. We made the point that the relatively nominal sum being offered wasn't important, it is the fact of recognising what has been done to people and the harm that will be done by refusing to acknowledge that somebody was the subject of research when they have spent decades compiling evidence to prove that they were.

f) Sir Robert concluded the meeting by saying that he and Mr Foley would very much like to meet with us again which we found both odd and irritating. We found the sentiment odd because the meeting had not been productive in any way (at least insofar as we could tell) and irritating because it added to the growing sense (which we will describe fully later) that the IBCA is keen to make the right noises about consultation but actually does very little with the information which it receives from infected and affected people.

External Support and Assistance

28. With the exception of the £2,200 that was paid to our solicitors for work conducted on the early stages of the IBCA's consultation, the IBCA has not

offered or facilitated any other external support or assistance for campaigners or campaign groups. As we noted at the outset of this statement, the IBCA has placed campaign groups in the invidious position of being the representatives for the entire infected and affected community on issues which we do not have the training to fully understand.

29. The IBCA has all but refused to actively engage with our legal representatives; RLRs are usually consulted on topics after campaign groups and are not given advanced sight or warning of proposals emanating from the IBCA. Our own solicitor does not receive updates from the IBCA despite registering with them and having raised the problem with IBCA staff – in consequence, we have to forward everything we receive to him so that he is able to see what is going on.

30. Our solicitor has continued to support us since May 2024 despite not being paid by the IBCA to do so; we understand that other RLRs have continued to support their clients on a similar basis. This help has been invaluable in understanding the main points of the scheme's regulations as well as what proposals and developments will mean in practice for individual claimants.

31. Our impression is (not least because of our most recent meeting with Sir Robert) that the IBCA has consistently sought to minimise the role of legal representatives; We can only presume that this is through the misguided view that they will save costs by doing so.

32. We describe the view as misguided because it is our understanding that the IBCA is in the process of hiring 900 claims managers to effectively repeat the tasks that will have to be undertaken by our lawyers in any event in order to adequately advise us. We have estimated that over the course of six years, the total cost of 900 case managers will be at least £400m which seems somewhat wasteful considering that the same work will be undertaken in any event by people who we have known for seven years and who we trust.

33. It is of course right that the IBCA and the Cabinet Office should consult with the infected and affected community about the shape of the compensation scheme

but if the IBCA had wished to do that in the most efficient and sensitive way possible then surely the most logical approach would have been to engage with the RLRs from the outset: the RLR's know the history, they know what we want to see from a scheme and they collectively represent a majority of those who are infected.

Our Involvement in IBCA Decision Making

34. It would be wrong to say that infected and affected people have had no involvement in the decision-making regarding compensation but it would be fair to say that they have had no meaningful involvement.

35. As we have noted above, the IBCA has, from the outset, held relatively regular virtual meetings with campaigners and campaign organisations, they also have an email address where concerns about the compensation scheme can be sent and from which, a reply is usually received.

36. Additionally, views are occasionally sought from the infected and affected community about specific issues (such as currently, the prioritisation of invitations to claim).

37. Finally, as we noted above, in summer 2024, we were invited to make written submissions ahead of Sir Robert's recommendations which themselves, preceded the Infected Blood Compensation Scheme Regulations (2024).

38. This is the extent of our involvement in the IBCA's decision making processes.

Issues with our involvement in IBCA decision making

39. The IBCA has done a very good job of perfecting a veneer of collaboration whilst proceeding to do precisely what it planned to do before it entered into discussions with the infected and affected community.

40. With the exception of the written submissions which were made in summer 2024, we cannot recall a single instance where the IBCA has changed course

because of something said to it by or on behalf of, the infected and affected community.

41. From our first meeting with the IBCA in May 2024, we have always had the sense that their proposals are presented to us as a *fait accompli* and whilst they would like us to approve of those proposals, they aren't prepared to change course if we don't.

42. Throughout our meetings with the IBCA, all the right things are usually said – *"that's a good point which we need to think about", "we'll take that away", "we have found your input extremely helpful"* – but nothing changes as a result of what we have to say.

43. Over and above this, even if the IBCA was interested in what we have to say, they often don't consult on points of importance but do consult on points which are of peripheral importance or which seem likely to provoke dispute amongst the various factions of the community. In this regard:-

    a) Anybody with even a vague knowledge of the Infected Blood Inquiry knows that (largely because of the historic actions of various governments) there are differing views amongst those infected and affected about how support and compensation should be handled. There are different interests amongst the community and there are strong feelings about ensuring that each faction is adequately represented. Over and above this, many remain haunted by their experiences with the Alliance House Organisations and are deeply concerned when parallels between the IBCA and say, the MFT arise.

       In spite of these concerns, the IBCA decided to appoint User Consultants without any discussion with the community and with no apparent regard for the concern that those appointments would cause. We don't suggest any fault on the part of the individuals who have been appointed but rather pick fault with the IBCA for making the appointments when it has (i) been unable to explain the rationale for the existence of the positions, (ii) unable to explain what the consultants will do on a day to day basis, and (iii) appears only to have made the appointments as a show of involving the community in decision making processes.

It is our belief that had the IBCA consulted on whether these positions ought to exist, the community would have largely spoken with one voice and said that they should not.

b) As we noted above, the IBCA has consulted on the order of priority for issuing invitations to make core route compensation claims. The IBCA has sought views from the community whilst the community doesn't have the requisite information to express informed opinions – we do not know the anticipated timescales for the IBCA ramping up capacity to allow applications to be made without invitation, we do not know whether there will ever be the ability to make an application without invitation and we do not know when affected people will begin to be able to make applications.

   It is therefore entirely predictable that the IBCA will receive dozens of different suggestions about who should take priority, with each campaign organisation advocating that those they represent should be at the front of the queue. If we knew for instance, that the scheme would be open to general infected applications within a matter of weeks, the issue might not be so heated but the very fact that the consultation is taking place suggests that it will be a considerable amount of time before all of the infected registrants of the IBSS will be processed.

   In our view, the IBCA should not have consulted on the issue – the consultation was only ever going to yield further anger and division without providing any useful information to inform decision making. The IBCA should have adopted the objectively fair mechanism we previously described whilst simultaneously doing more to speed up the increases in its capacity.

c) The IBCA did not consult on the adoption of a framework based upon claims managers being employed to prepare a person's claim. Had they done so, we believe that the community would have largely spoken with one voice to say that this is not something we wanted. We do not want to have to deal with a claims manager whom we have to (again) repeat our histories to, work with to provide our medical records, and explain to them the significance of each individual document. There is no need for us to do this when the majority of us have legal representatives who already have our medical records, who know our histories and who are better equipped to prepare our claims for us.

It might well be appropriate to have a small number of claims managers to assist people who choose not to have legal representation but to impose those claims managers on people who do not want them is wrong.

d) The IBCA is currently consulting on unethical research awards and whilst we think that this is an area where consultation may be appropriate, it is also an area where the results of that consultation are entirely predictable; as we noted previously, you would be hard pressed to find an infected haemophiliac who does not consider that they were experimented upon. It is probably right that there should be an expedited process to make the award for known research projects such as at Treloars but the simple solution is to have a separate route to make a claim for this award for anyone who considers that they have evidence that they were the subject of unethical research. There would have been no need to consult if the IBCA had simply arrived at this logical conclusion from the outset.

44. Through these examples, a pattern emerges: the IBCA does not seek the views of the community on areas where there is likely to be a uniform response; particularly when that likely response runs contrary to what the IBCA intends to do. The IBCA does however consult on issues where division amongst the community is likely, presumably so that amongst the differing views, they can present their predetermined route as a middle ground or compromise.

45. The message which we want to convey in the strongest terms is that the engagement exercises undertaken by the IBCA have been, in our opinion,

shallow, meaningless and 'for show'. We are left with the opinion that the IBCA has been careful to take a range of steps to ensure that, should they come under scrutiny, they can point to dozens of meetings with campaigners, reems of correspondence with infected and affected people and the appointment of user consultants to show that the community has been involved in the IBCA's decision making processes. Those steps however, are worthless when one realises that no regard whatsoever is being had to what the infected and affected people have to say.

46. The compensation scheme has been, since its announcement on 21 May, a pre-determined framework to which only the illusion of collaboration with the community has been attached.

47. It is for all of these reasons that we describe the IBCA as the MFT on steroids.

Impact of our engagement with the IBCA

48. Exhausting, dispiriting, and depressing are the first three words that we would use to describe our experiences over the past eight months with the IBCA and Cabinet Office.

49. Disillusioned and disappointed are two more. On 20 May 2024, we read the Inquiry's report and listened to Sir Brian's words in a state of almost disbelief: that after decades of fighting and campaigning, the truth had finally emerged, there was a common sense that the fight was over. From 21 May, the Government began to take that victory away and over the course of the last eight months, has taken us back to the days of fighting with the MFT at every turn.

50. As we have already set out in this statement, the IBCA has all but refused to actively engage with legal representatives and instead, has labelled the campaign organisations as 'community representatives'. The IBCA has placed upon us all a burden which we did not have to, and should not have had to, bear but for the IBCA's dogged refusal to faithfully engage with the RLRs who

are far better placed than we are to contribute to the design of a compensation scheme.

51. We have had to field calls and emails relentlessly since May from community members who are scared and anxious about whatever the IBCA next announces it intends to do. We have had to do this without always fully understanding the framework and regulations ourselves and reliant upon our legal advisers largely working on a pro-bono basis.

Impact of the IBCA's actions on the wider community

52. In our experience of talking to our other campaigners and members of the community more generally, there is an all-pervading sense of depression, fear and suspicion. There is no trust in the IBCA's independence, no faith that it seeks to act in our best interests and no sense that we are coming to the end of a very long journey towards justice.

53. Some people are scared that they won't be compensated in time to utilise their awards to ensure that they are able to enjoy what is left of their lives. Some people are scared that they won't be compensated in time to put their affairs in order and ensure that there is provision for their families once they are gone. Some people are scared that that they will need to fight for another decade or more just to get what Sir Brian said they should get.

54. No member of the community should be living in a state of fear which has been directly caused by the Government's response to the Inquiry's report: we all have enough to fear from our infections and the health conditions arising from them.

55. All any of us want now, is to be paid our compensation and to be left alone to get on with the rest of our lives.

Steps which might be taken to improve the IBCA and IBCS

56. We believe that if the IBCA were to take the following steps, it may help to alleviate some of the detrimental effects which have been caused by its actions to-date:

    a) Stop relying on exhausted campaigners as representatives of a diverse body of people because of an apparently ideological opposition to engaging with our lawyers. Engage with our legal representatives on the design of the scheme. This will not only ensure that the scheme reflects the community's broad wishes but will also yield a far more efficient consultation process than endless meetings which collect together people who it often feels are being set up to argue amongst themselves.

    b) Actively listen to what is said on the community's behalf; do not present proposals as a *fait accompli* and use engagement exercises as a justification for doing what you had planned to do in any event.

    c) Be frank and transparent with the community; we refuse to believe that the IBCA has no assessment of how long it will take to process the claims of all those currently registered with the IBSS. Tell us what that assessment is and manage expectations – telling us that you are working as quickly as possible without actually telling us what you are doing to increase capacity, does nothing to alleviate anyone's concerns.

    d) Rather than single-mindedly pressing ahead with the case manager led system, consider how applications might be processed more quickly if you simply allowed us to instruct our solicitors to prepare our claims and declaration forms and submit them directly to an assessor. It seems to us that this might have the effect of immediately and dramatically increasing the IBCA's ability to process claims whilst also potentially saving a significant amount of the planned expense on those case managers.

    e) Give some thought to what is being written in IBCA updates and how that might be read by the intended audience: write those updates with empathy. Sending an update 20 months after the Inquiry's final word on compensation was published, boasting that the first ten claimants have now been paid does little for the community other than demonstrate the glacial pace at which the Government has moved on the entire issue of compensation. We would far rather hear about what steps you are taking to ensure that nobody has to wait another minute longer than is absolutely necessary for their award,

Concluding Comments

57. On 20 May 2024, the prospect of giving another witness statement to the Infected Blood Inquiry seemed so completely improbable that it was inconceivable. It is a mark of how poorly the Government has responded, that the Inquiry has felt compelled to issue further Rule 9 requests. We are glad that those Rule 9 request have been issued; our experience of dealing with Government is that they will only change course when they are compelled to do so, or subject to sufficient scrutiny in a public forum.

58. We sincerely hope that the IBCA will change course before it is too late and before they cause irreparable further harm to infected and affected people.

59. Finally, we wish to acknowledge that this statement is deeply critical of the IBCA, Cabinet Office and Government generally as bodies. We don't direct criticism towards individuals within those bodies per se; our engagements with the IBCA staff and Cabinet Office civil servants have always been respectful. Nevertheless, we do think that those individuals might be assisted by returning to Volume 1 of the Inquiry's Report and re-reading page 14 where Sir Brian wrote:

    "The fifth theme is that of institutional defensiveness, from the NHS and in particular from government, compounded by groupthink amongst civil servants and ministers, and a lack of transparency and candour. These factors drove the response of government over the decades.

> *The institutional defensiveness identified above is damaging to the public interest. But the sixth principal theme that emerges from this Report is the damage that was done by that defensiveness and the accompanying lack of transparency and candour to the very people whose lives had been destroyed by infection. The harms already done to them were compounded by the refusal to accept responsibility and offer accountability, the refusal to give the answers that people fervently sought, the refusal to provide compensation, leaving people struggling and in desperate circumstances, the thoughtless repetition of unjustified and misleading lines to take, and the lack of any real recognition and of any meaningful apology."*

60. Sir Brian's findings in this regard, seem to us to be as relevant to our experiences of the IBCA as they are to the events which took place over the last four decades and to which, Sir Brian was referring.

Statement of Truth

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

Signed:... GRO-C ....

WITN1387

23 January 2025

Dated ____________________________

Signed GRO-C

Alan Burgess

23 January 2025

Dated ____________________________

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**
21/05/24	Infected Blood Compensation Scheme Proposals	WITN7752002
27/05/24	Email to Cabinet Office	WITN7752003
June 2024	Infected Blood Compensation Scheme Proposals Explainer	WITN7752004
28/06/24	Letter from Milners Solicitors to the IBCA	WITN7752005
August 2024	Recommendations from Sir Robert Francis on IBCS Proposals	WITN7752006