

Witness Name: Alan Burgess

Statement No.: WITN1122049

Exhibits: 0

Dated: 24 March 2021

INFECTED BLOOD INQUIRY

FOURTH WRITTEN STATEMENT OF ALAN BURGESS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 February 2020.

I, Alan Burgess, will say as follows: -

Section 1: Your Role and the Structure of the Haemophilia Society

1. Please confirm and outline your role and the responsibilities within the Society. If these changed over time, please detail when and why.

1. I was a trustee of the Haemophilia Society from October 2014 to July 2015; my responsibilities were to attend board meetings and liaise with other trustees on matters concerning the operation of the Society.

2. When you joined the Society, and throughout your tenure, what was your understanding of the objectives and functions of the Society? If these changed over time, please detail when and why.

2. The objectives of the Society were to raise awareness of and provide support to those diagnosed with bleeding disorders, to raise money and to distribute this money to causes which would either advance research into bleeding disorders and their treatment or to assist those diagnosed.
3. The objectives of the Society did not change whilst I was a trustee.

3. Please list any Haemophilia Society sub-committees, task groups and/or advisory bodies that you were involved with; describe your understanding of the purpose, functions and responsibilities of any such committee, task group and/or advisory body in which you were involved; and provide details of your role and involvement.

4. I did not sit on any committees, task groups or advisory bodies during my time at the Society.

4. Please explain your working relationship with the Chief Executive and other trustees in your role in the Haemophilia Society.

5. I had a good relationship with Liz Carroll who was the Chief Executive whilst I was a trustee. I had mixed relations with the other trustees, some were happy to talk about and take action in relation to contaminated products and infections, but others showed no interest and refused to engage on the topic.
6. For some trustees, HIV and HCV infections were an issue to sweep under the carpet, an issue of the past which they wanted to ignore in order to focus on the younger generations of haemophiliacs who had avoided infection.
7. One example I remember of this was the refusal of the board to agree any kind of event or recognition of World AIDS Day despite so many haemophiliacs having died of AIDS and so many still infected with HIV.

Section 2: Relationship with the Government

5. Please describe the extent of your role and involvement (if any) with regard to the Society's interactions with and representations to the Government.

8. I had no role which involved contact with the Government and I was never involved in any meeting with ministers, civil servants or ministerial departments.

9. My only interaction with politicians in my capacity as a trustee of the Society was in January 2015 when I was asked to give a talk to the APPG on Haemophilia in parliament. I spoke to the APPG about my time as a user trustee of the MFT and gave a personal account of my experience of having been infected with HIV and HCV and how this had impacted my life and that of my family.

6. If you attended any meetings with Government ministers and/or civil servants and/or other representatives of Government, please provide as detailed an account as you can of those meetings.

10. I did not attend any such meetings.

2.1 Campaign for an Independent Public Inquiry

7. During your tenure, what role, if any, did the Society play in seeking an independent public inquiry? Please set out chronologically any knowledge you have of the Society's campaign and/or involvement in the campaign for a public inquiry.

11. I am not aware of the Society having played any role in seeking an independent public inquiry. During my time as a trustee of the Society, the advocacy and campaigning was focussed on formulating a response

to the Penrose Inquiry and preparing representations for the APPG's inquiry into the operation of the AHOs.

8. Did you participate in, or were you aware of, any discussions between the Society and the Government with regard to an independent public inquiry? If so, please provide details.

12. I was not aware of, and did not participate in, any discussions between the Society and Government regarding a public inquiry.

9. In June 2009, Philip Dolan raised his concerns that the Haemophilia Society was “doing less than it could or should as a campaign group” with regards to encouraging the Department of Health to implement the findings of the Archer Inquiry [MACF0000012_011]. Did you share these views at the time? If so, please explain the basis for your views.

13. The Archer Inquiry examined the suffering experienced by the haemophilia community, but it didn't examine how the situation had arisen or who was to blame.

14. I agreed with Philip that the Society could have been louder in its calls for the Archer Recommendations to be implemented in full, but this was only half of the equation. I wanted to see the Society campaign for a national, statutory public inquiry so that the community could finally see the truth about how we had all come to be infected with HIV and/or HCV.

15. The Society had, in my view, two problems calling for a statutory public inquiry and the first of these was that, as I have previously mentioned, the Society wanted to move focus away from the infected haemophiliacs of the past and toward the new generation. I think this was driven by an idea that the new, uninfected generation of haemophiliacs were more presentable for fund raising purposes.

16. The Society's second problem was that its actions (or omissions) during the 1980s particularly, contributed to the scale of contaminated blood products scandal. It would never be in the Society's interests to have a public inquiry which examined the causes and scale of the scandal for this reason.
17. This second problem makes it all the more bizarre that the Society did not throw all of its energy into campaigning for the Archer recommendations to be fully implemented via the passing of Lord Morris' Contaminated Blood Bill. If the Bill had been passed then a lot of the financial difficulties faced by the community would have disappeared and in turn, the voices of many of those calling for a full public inquiry might have been quietened.

Section 3: Relationship with the Birchgrove Group

10. When you joined the Birchgrove Group, and throughout your tenure, what were the objectives and functions of the Group? If these changed over time, please detail when and why. In your answer, please detail the relationship between the Haemophilia Society and the Birchgrove Group.

18. The Birchgrove Group was formed to support haemophiliacs and their families who were infected or affected via contaminated blood products. Support was given by providing help and advice on the full spectrum of difficulties that the haemophilia community were facing as a result of their infections.
19. The Birchgrove Group gave its support in a number of different ways, the most obvious was the Newsletter which discussed things such as new treatments but also practical advice on shared problems – at one time, when the inconsistency of the MFT was particularly bad, we used to publish lists of items for which we thought applications for grants would be successful.

20. Over and above this, the Birchgrove Group was at the forefront of campaigning for justice for infected haemophiliacs and their families and particularly, leading calls for an independent public inquiry.

21. Birchgrove's relationship with the Society was complicated and is an example of the way in which the Society wanted to distance itself from the events of the past.

22. As I understand it, the Society received funding from central government to advocate on HIV and AIDS related issues but, wanting to distance itself from infected haemophiliacs, did not want to be seen to be advocating on the issue. The Society transferred the funds it received from Government to Birchgrove so that we could do this work and Birchgrove were authorised to use the Society's charity number on publications.

23. At the time, the relationship between the Society and Birchgrove was distant and at times, difficult; at Birchgrove, we felt like infected haemophiliacs were treated as a stain on the Society's membership, an embarrassment.

24. I was Chair of the Birchgrove Group at the time, and I took the issue up with Karin Pappenheim who was then the Society's CEO. Eventually, the Society agreed to appoint a HIV/HCV Co-Ordinator and I was invited to sit on the interview panel; GRO-D was ultimately appointed.

11. Please confirm and outline your role and the responsibilities within the Birchgrove Group, including responsibilities held in relation to the Haemophilia Society.

25. At the time, I lived in Suffolk and aside from the occasional Society Publication, I felt cut off; I was alone and frightened for the future, unsure in many respects about the consequences of my infections. In one of the

Society's publications, I saw an advert for the Birchgrove Group and I wrote to them; a few months later, I attended their conference in Manchester which was one of the best things I have done. I met other people with similar circumstances to me and I was able to talk freely about all the issues and questions I had about being a haemophiliac infected with HIV and HCV. I struck up many lifelong friendships though for many of those friendships, "lifelong" wasn't particularly long; many of the people I met on that first weekend have now died at young ages and in large part, it is the memory of those friendships that has kept me fighting.

26. In March 1995, I joined Birchgrove's steering group and then, along with [GRO-A] and [GRO-A] I was appointed as a Birchgrove representative to the Society where I would attend occasional meetings with the Society to discuss issues being experienced by the infected community.

27. Later in 1995 [GRO-A] and I took over responsibility for the relationship with the Woodland Trust which concerned work started by [GRO-A] and [GRO-A] on the creation of a Birchgrove Memorial Site. [GRO-A] and I took over as [GRO-A] and [GRO-A]'s health failed.

28. After [GRO-A] and [GRO-A] died, a Woodland Working Group was established by Birchgrove which I sat on; the work of this group (and the work that came before it) came to fruition in 2004 with the opening of the Birchgrove Woodland Grove in Swindon; it was a very proud day for me.

29. In 1998 I became Chair of the Birchgrove Group and served until 2003, I had originally joined Birchgrove in 1994.

12. The minutes of the first meeting of the National Birchgrove Steering Group [GLEW0000546], held on 4 and 5 March 1995, references future meetings between the Society and the Group. How often, to your

knowledge, did these meetings occur? If you attended them, please outline what issues were discussed at them.

30. Insofar as I recall, the Birchgrove Group and the Society met infrequently and I went to some of these meetings but I cannot remember the specifics of discussions. As Chair of the Birchgrove Group, I had some telephone calls in additions to meetings with Ann Hithersay and Chris Hodgson. Meetings were typically about current issues with treatments, infections or similar topics as well as issues that Birchgrove's membership were experiencing either with the Society or the MFT.

31. The only meeting I remember with any clarity was the informal meeting we had with Ann Hithersay which I referred to in my third written statement and where we sought Ann's advice on how to address the inappropriate emails which had been sent by Peter Stevens.

13. In the minutes of the first meeting of the National Birchgrove Steering Group, held on 4 and 5 March 1995, the Steering Group "agreed that there was a need to coordinate and formalise concerns expressed by local group members" [GLEW0000546]. Did any of these concerns pertain to the Haemophilia Society? If so, what were they?

32. I'm sorry, but with the passage of time, I cannot remember what this minute relates to.

14. In the minutes of the first meeting of the National Birchgrove Steering Group, held on 4 and 5 March 1995, it is reported that the Society had asked for Simon Taylor to attend National Steering Group meetings [GLEW0000546].

a. Did this happen?

33. Yes, I believe that Simon Taylor did attend a meeting of the National Steering Group but I cannot remember how many meetings or even if it was more than once.

b. If not, why not (as far as you are aware)?

N/A

c. The minutes note that the reaction to this suggestion was “mixed” - could you please elaborate? Why was the reaction mixed? What were the arguments in favour of, and against, the proposition?

34. I cannot remember the specifics of the discussion, but there was a deep mistrust of the Society amongst not only the members of the Birchgrove Group but large parts of the haemophilia community generally. I think that this mistrust ultimately stemmed from the fact that throughout the 80s, many haemophiliacs had done exactly what the Society had advised them; they had taken their medicine in spite of the media warnings about AIDS and as a result we were all infected with HCV and many of us, with HIV. The Society was a mouthpiece for the UKHCDO rather than a safeguard for haemophiliacs.

35. Added to this was the sense that the Society was at best neutral though probably more accurately, partisan against haemophiliacs in any attempts to go to Court to get some form of justice. The Inquiry has already seen that the Society was sharing its legal advice on the 1990/1 litigation with the UKHCDO – we didn't know that at the time but it's hardly a surprising revelation now.

36. Over and above this was the move by the Society, through the 1990s, to distance itself from infected haemophiliacs; I have already explained that we were made to feel like an embarrassment.

37. The Birchgrove Group had been founded as an independent group to support and advocate for infected haemophiliacs and I think there was apprehension about allowing the Society to get too close when we considered that they had failed in this support and advocacy role previously.

15. In the minutes of the first meeting of the National Birchgrove Steering Group, held on 4 and 5 March 1995, the Steering Group stated that “the Haemophilia Society should act as a forthright advocate for those with haemophilia and HIV and their families” [GLEW0000546].

a. In the opinion of the Steering Group, was the Haemophilia Society succeeding in this role?

38. No, as I have set out above, we did not think that the Society was succeeding as an advocate nor had they historically succeeded.

b. In your opinion, was the Haemophilia Society succeeding in this role?

39. No, I did not personally think that the Society had been very successful. The Society is good at talking about haemophilia minus the infections, but it has always failed to sufficiently recognise that for the last 45 years, it has been AIDS and HCV killing haemophiliacs, not their haemophilia.

40. The whole reason why the Birchgrove Group was set up was because a group of haemophiliacs and their families felt that no one (including the Society) was advocating, campaigning or fighting strongly enough to have their voices heard. This was how I felt and it is why I joined the Birchgrove Group.

Section 4: Previous Evidence

16. In your oral evidence to the Inquiry, on 28 October 2019, you stated that the Haemophilia Society was “too cosy with a lot of the pharmaceutical companies who obviously gave a lot of us -- I mean BPL were British, but a lot of the pharmaceutical companies were sponsoring certain Haemophilia Society events and things like that, so they were too close” [Transcript, page 102, §1-5]. Please can you detail the relationship between pharmaceutical companies and the Haemophilia Society, in particular:

a. To what extent did the Society rely on financial contributions from pharmaceutical companies manufacturing and/or supplying blood products?

41. I knew that the Society historically had ties to the pharmaceutical industry, and I knew that the pharmaceuticals gave donations, provided branded promo goods and sponsored trips to conferences.

42. When I became a trustee of the Society, I began to fully appreciate how close those ties were and how much the Society relied upon the pharmaceutical industry for funding. It was the 2015 funding report from the minutes of the Society’s board meeting in February 2015 that gave me this awareness.

b. Please explain any differences in the Society’s relationships with the different pharmaceutical companies. For example, were there some pharmaceutical companies that donated more, in terms of frequency and/or amount, than other pharmaceutical companies, to the Society? If so, which ones?

43. I do not know how the relationships varied with different pharmaceutical companies, my only knowledge that the relationships still exist (or at least, existed in 2015) came from the minutes which I have previously referred to.

c. What, in your view, were the motivations or expectations, if any, of pharmaceutical companies who donated to the Haemophilia Society? Was there an expectation that the Society would provide anything in return and if so, what?

44. I can't imagine that the companies gave money for no reason, I expect it was intended as a recognition of the amounts spent on behalf of UK haemophiliacs with these companies, but I have never seen anything to explicitly suggest that there was any sort of transactional nature to the Society's relationship with the pharmaceuticals.

d. To what extent, did the Haemophilia Society, through its activities and functions, attempt (if at all) to assist pharmaceutical companies to promote their products and/or public image? If so, please provide details, specifying the pharmaceutical companies, the products, the Society's activities and functions, and the way in which these activities and functions promoted the pharmaceutical companies products and/or public image.

45. I don't know that there was any explicit acknowledgment by the trustees that the Society was promoting the pharmaceuticals but by distributing their merchandise and otherwise dealing with them, the Society was implicitly endorsing them.

e. Did the Society publish or disseminate any articles or publications in exchange or with the expectation of receiving financial contributions, or any other benefit, by pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

46. I do not know the answer to this question.

f. Did the Haemophilia Society refrain from publishing or disseminating any articles or publications in exchange or with the expectation of receiving financial contributions, or any other benefits,

from pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

47. Again, I do not know the answer to this question save that I'm not aware of this ever having happened.

g. Did the Haemophilia Society rely on pharmaceutical companies for assistance or support, other than financial contributions? If so, please provide as much detail as possible on the support provided, the specific activities/functions that pharmaceutical companies supported, and the names of pharmaceutical companies involved.

48. I am only aware of the levels of financial support which the Society received; the 4 February 2015 board meeting is clear on the levels of financial support being given with Bayer being the main contributor.

17. In your oral evidence to the Inquiry, you stated that "there was a particular chief executive there who really kept us at arm's length" [Transcript, page 102, §17-19].

a. Who was this?

49. I was talking about Karin Pappenheim.

b. Please elaborate on how they kept you at "arm's length" and your understanding of why this was.

50. I was talking about the sense I've discussed elsewhere in this statement that the infected community seemed to be a source of shame or embarrassment to the Society; it was the reason we felt we didn't have a voice.

c. What impact did this have on you and the Group?

51. The attitude of the Society had a positive effect in a strange way. The Society's failure to properly represent and advocate on our behalf led to Birchgrove becoming more vocal and eventually, acquiring the Society's funding for AIDS advocacy. This in turn meant that we were able to campaign in ways which the Society never could or would have and which at least made the members feel as though someone was speaking up for them.

Section 5: Other Issues

18. Please explain, in as much detail as you are able to, any other matters that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.

52. I had an unsatisfactory ending to my time as Society trustee. It stemmed from the January 2015 meeting that Liz Carroll had with Roger Evans and Jan Barlow.

53. As it has been documented many times now in this inquiry the board of MFT were threatening legal action against the Society and Liz Carroll personally. On the Society board we had **GRO-A** who was also a trustee of MFT. I felt strongly that as a board member I wanted to know if **GRO-A** had voted as a trustee of MFT to take legal action against the Society and Liz because that would have meant he was in a sense, suing himself as he was a Society trustee. We all knew that if legal action was taken, it probably would have led to the Society having to close as it was in no position to pay legal fees let alone damages.

54. Despite pushing, I was never given an explanation or told how much **GRO-A** was involved in the MFT decision to threaten legal action. Liz ended up apologising to MFT in what was supposed to be an end to the dispute, but with **GRO-A** still a trustee and without explanation of what role he had played in the dispute (if any) I felt I couldn't serve on the board any longer and I resigned.

55. I have since learned, from Liz Carroll's written statement that GRO-A also offered his resignation, (although the reasons are unclear) and it was turned down.

56. GRO-D
GRO-D
GRO-D It remains unclear to me what role Society appointed trustees had in the MFT's decision to threaten the Society and Liz Carroll with legal action and I was concerned by Roger Evans' oral evidence where he said that the Board of the MFT were unanimous in their decision to instruct lawyers in relation to the dispute.

Statement of Truth

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

Signed GRO-C

Dated 24 March 2021