

Witness Name: Alan Burgess

Statement No: WITN1122005

Exhibits: 0

Dated: October 2019

## INFECTED BLOOD INQUIRY

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### SECOND WRITTEN STATEMENT OF ALAN BURGESS

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I, Alan Burgess will say as follows:-

#### Section 1. Introduction

1. My name is Alan Burgess and I was born on [GRO-C] 1958. I live at [GRO-C] [GRO-C] Suffolk, [GRO-C] with my wife, Denise. We have three children; Sarah, Laura and Liam.
2. I make this statement pursuant to the request under Rule 9 of the Inquiry Rules, dated 4 September 2019 and further to my First Written Statement on which I continue to rely.

#### Section 2. The MacFarlane Trust (MFT)

3. I applied for a position as a User Trustee when the MFT advertised as I thought I could get involved to make a difference. I attended my first Board meeting in the late 2008/early 2009. During that time the MFT and HIV/AIDS community knew it was a tough challenge because of the lack of government funding. I sat with other User Trustees and our aim and efforts were spent in making the MFT a more proactive Charity as opposed to reactive. We wanted the MFT to get funds from the Government but we were always restricted with

a budget and I tried to make a difference for when requests came in from the beneficiaries.

4. I sat on the main Board which had two or three sub-committees; one of them was called the National Support Services Committee (NSSC) chaired by Elizabeth Boyd (a Trustee appointed by the Department of Health (DOH)) which was a sub-committee dealing with incoming requests. We met every 4 to 6 weeks but we realised we had nowhere near enough money to satisfy the requests. It was frustrating because we always received complaints from the beneficiaries but our hands were tied.
5. I had a lot of respect for the personnel of the MFT in the early days when I was a Trustee, in particular Christopher Fitzgerald (the Chair) who was very approachable.
6. In 2012, Christopher Fitzgerald had to stand down and was replaced by Roger Evans. A short while later, Jan Barlow replaced Martin Harvey who had to retire on the grounds of ill-health. As a result of this, things at the MFT changed overnight.
7. We fought for years to make the MFT more accountable. In the early days they didn't even talk to us and didn't even tell us where our offices were. It was like the Trustees were faceless but we kept going. After a lot of hard work we managed to set up the Partnership Group which took the dialogue between the Trust and the beneficiaries further. At least then the beneficiaries had a forum to get things done.
8. The Partnership Group set up a regular newsletter from the Trust relating with news which the beneficiaries needed to be kept updated on. We secured help from the MFT for events such as weekends away which were very important. We initiated "Men Only Weekends" because we found that the men, including myself, would not open up as freely when our partners and wives were present. During these meetings we had the chance to get together and talk openly about our experiences. It was not a stag-do but a place to get together which involved counselling.

9. Widows and families also attended separate events and we moved on quite well with these. We all thought it was breath of fresh air. Christopher Fitzgerald and Martin Harvey were there and we felt it should have been like this from day one but it wasn't. It gave individuals a chance to receive support and comfort especially as, for some members, it was the only time they ever discussed what they have been through.
10. In the early days of the internet we created a Bulletin Board at the MFT with the help of Andy Evans for beneficiaries to access and be able to find out recent news and developments. It was like a very early Facebook which we felt was a positive invention. It got sad at times due to people's comments but by the large it was a step which served a valuable purpose.
11. When Roger Evans and Jan Barlow were appointed, they closed down the Bulletin Board as they thought it provided too much misinformation and too many personal attacks on them. It was the first decision they made together and it was awful to cut off the support line from the beneficiaries. They thought that they could prevent us from talking to each other in an attempt to divide us and conquer.
12. When I became a Trustee, I used to attend the Partnership Group meetings as both a Trustee and a Beneficiary. From around 2005/2006 beneficiaries used to get a winter fuel allowance because people who suffered from HIV and HCV needed to keep warm in the winter which meant that their heating would have to be on for longer periods of time. It started off as a small monetary amount which eventually rose to £750 annually (paid at the end of November/beginning of December) to help with winter bills. One very, very cold winter an extra one off payment of £150 was given. I recall receiving a phone call from Roger Evans one night before a Partnership Group meeting was due to convene. He referred to George Osborne's austere times and announced that the winter fuel payments would be withdrawn. He told me that, as a Trustee, I needed to be completely supportive of his decision. I

refused to support him telling him that the reason for the allowance was health grounds and therefore I could not and could not support his position.

13. At the Partnership Group meeting he sat there like a Government Minister and openly spoke about austerity and proposed to take away the allowance that year. I was outraged, not just as a beneficiary, but as a human being. This related to people's health and wellbeing. Roger Evans argued that after the Archer Inquiry recommendations (a few of which were actually taken on by the Government) a monetary uplift had been awarded to those infected and affected which he thought would enable people to afford things such as the winter fuel bills. The prominent problem and a misunderstanding on his part was that we were not only playing catch-up with monthly bills, but people had been on the breadline for many years which meant that they relied heavily on winter fuel payments.
14. I did my best to fight against Roger Evans' proposed decision and said that the winter fuel payment would be taken away over my dead body. Unfortunately another User Trustee supported Roger Evans and gave me (and consequently the beneficiaries) no support at all.
15. Additionally, we used to get discretionary pay following the Archer recommendations. This was means-tested and increased every year in line with inflation. Once more, Roger Evans waved austerity in our face and announced that the MFT could not afford the inflationary increase which was awful. It meant that some beneficiaries were effectively facing a 4% cut along with the reduced winter allowance.
16. A pattern was emerging. In essence they took money away from the beneficiaries. There were other ways in which the MFT could have saved money such as relocating their offices. When I proposed this they told me that they could not move. I wondered why they always looked to the beneficiaries to make cuts and I specifically raised this question with them. When I attended other Charity offices such as the Thalidomide Trust in Bedfordshire, it was a breath of fresh air. They treated their beneficiaries with respect, unlike the MFT. How did they manage to get £90m funding from the Government?

They kept banging on their door. I cited the Haemophilia Society as another example of a Charity who faced financial difficulties at the time and moved offices to try and tackle the problem. I went back to the MFT to say we needed to do more and they told me that the MFT was "*not here to advocate*" which was absolutely disgraceful.

17. Russell Mishcon, who was a Trustee at the time, was a solicitor and pointed out that legally we could not discharge our duty in accordance with Charity law and we were not meeting legal requirements if the MFT continued like this. Both Russell Mishcon and Elizabeth Boyd were very concerned. They spoke with MP Alastair Burt and voiced their concerns that the MFT was not being run to the advantage of the beneficiaries. They also wrote to both the Charities Commission and Secretary of State for Health (Jeremy Hunt) to outline their concerns about how the MFT was being run.

18. Russell put together a letter that he wanted the Trustees to sign and send to the DOH outlining that it was difficult to discharge their duties as Trustees and therefore they required more money to do so. When Roger Evans and Jan Barlow saw the letter they went berserk and refused to send it. Some of the reasoning provided by Roger Evans stood as follows:

*"the money is simply not there",*  
*"don't bite the hand that feeds you",*  
*"we are not prepared to rock the boat",*  
*"let's not forget the DOH set up the MFT and can close it down" and;*  
*"there's only one winner if you pick a fight with the Government".*

19. There were concerns across the board. We did not realise Roger Evans and Jan Barlow knew each other before she became the Chief Executive of the MFT. [REDACTED] **GRO-D**

**GRO-D** One of the beneficiaries who was a widow and was infected through her husband got her MP involved which caused a lot of irritation to Roger Evans and Jan Barlow. I overheard Jan Barlow say that if it was up to her, the widow wouldn't get another penny.

20. Jan Barlow announced she needed to employ a Head of Operations around the same time that cuts were being made to beneficiaries. Due to the already existing financial concerns, we had researched Jan Barlow and found that she had previously employed staff in her previous position at the Fire Brigade which was financially unfeasible. History was repeating itself.
21. Under Section 64 of The Charities Act the Government would offer money to Charities to cover administration costs. After approximately 2007/2008, this money came out of the beneficiaries' pot instead. When they refused to send the letter to the Government outlining we could not discharge our duty as Trustees we questioned Roger Evans' impartiality. He was acting like a Minister of a Department and not the Chair of a Charity. He was more concerned about the Government funds than acting in the best interests of the beneficiaries. In his professional life he was also completing jobs for the NHS which was I believe was a conflict of interest. We will never know the true story.
22. I refer to emails dated before the Archer Inquiry uplift in which Roger Evans states "*the MFT was there really to largely process funds*".
23. During a Board meeting on 21 January 2013 he said "*the MFT is the arm of the Government whether you like it or not*". I was, by this time, becoming increasingly frustrated and very concerned at the way the MFT was being run and this had a detrimental effect on my health. We pointed out that the Charity Commission Guidelines stated that one cannot act on behalf of the Government and be a Charity simultaneously. Roger Evans was appointed to consider the MFT concerns and not the concerns of the Government. I asked him to get clarification from DOH on how they expect the MFT to operate independently while restricting MFT's financial position.
24. To rub salt in the wound; two full-time posts at the MFT were created for an Operations Manager and a Financial Advisor. As a Trustee, I was gravely concerned with this because the deficit of the MFT for the year prior to this was £807,890. I asked questions because I was frustrated that the MFT were

cutting financial support to the beneficiaries yet advertising newly created positions worth £75,000 per annum.

25. Jan Barlow was the Chief Executive of the Caxton Foundation at the same time as she was the Chief Executive of the MFT. Although the Caxton Foundation had a different Chair it was just a different head on the monster. It transpired that the Caxton Foundation also made cuts to the beneficiaries and their annual winter fuel allowance was reduced from £500 to £350.

26. I told Roger Evans and Jan Barlow that I found their conduct shocking and appalling. I received a reply from Roger Evans after voicing my concerns as a Trustee. Part of his reply was:

*"I think we have reached a point where it is doubtful whether your continuing as a Trustee until the end period of your office is helpful or welcome. I doubt whether you and I can work productively together in the coming months given your latest correspondence. You may wish to consider resigning in expiration of your term of office."*

27. Approximately two or three weeks prior to their term at the office coming to an end Russell Mishcon and Elizabeth Boyd told me they would support me morally in voicing my concerns to Roger Evans and Jan Barlow. We arranged a meeting but Jan Barlow said she couldn't make it. During our meeting Roger Evans treated us with disrespect and our discussion became heated. He created a clique around himself including another User Trustees who didn't support me and sided with Evans and Barlow meaning that my arguments were easily ousted.

28. There was a mystic part about the information regarding finance of the MFT. At one point we had £4m worth of reserves which quickly decreased to £2m. Even during my time as a Trustee it was all a bit of a mystery. I recall that meetings between the Department of Health and the MFT were never minuted. The excuse given was that there were informal meetings but I called that into question as the meetings were usually about government funding to the MFT.

29. We campaigned for the reserves to be spent; the Government would surely tell us they couldn't provide any more money due to our reserves. I was asked (along with other User Trustees) to put a business case together on how the reserves could be spent. I spent a week working it out but before I got the chance to present my ideas they had already made a decision. I felt that we were not treated equally even though we were Trustees.
30. It was decided that an external company would go to people's homes to take photographs of work which needed to be done. We argued against this as it was intrusive.
31. Peter Stevens was the Chair of the Eileen Trust which had very few beneficiaries. It was like an incestuous family because the MFT Trustees were also the Trustees of the Eileen Trust which was very tightly knit and prevented the Charities from being as independent as they should have been. User Trustees (such as myself) were not allowed to do that.
32. For example, a beneficiary of the MFT was paid to organize Eileen Trust events. We assumed it was done on a voluntary basis. It became a problem because every payment from the MFT was tax free so had he put this into his account it would have impacted on his benefits. It transpired that they wanted it to be paid by the MFT which would constitute money laundering. Some of the MFT board wanted to do this but I, along with other Trustees, refused as we thought this would be dishonest practice.
33. I had an email from a member of staff who told me she had been treated appallingly and bullied by a member of staff which I assumed to be Jan Barlow. She had to get counselling for this terrible time in her life and felt she was forced to leave the MFT after 13 years of service.
34. I spent 6 years at MFT and the final 2 years were particularly difficult. I resigned from my position a day before I gave evidence to the All Party Political Group (APPG).



### The Haemophilia Society (HS)

35. I overlapped in my post as a Trustee for the MFT and the HS for approximately 9 or 10 months. In 2013, I knew my days at the MFT were numbered so I applied for a position as a Trustee advertised by the HS. The members balloted for me and I got the job. I thought highly of the HS and I thought I could do some good there.
36. It was standard practice for MFT and HS to conduct meetings which included 5 Trustees who sat on both Boards. At one point, Alan Tanner was the Chair of both charities.
37. I joined the HS when it was also facing financial difficulties as a result of the Government cutting their funding by £100,000. However, the HS adopted the correct practice by making redundancies, moving offices and downsizing
38. At a Haemophilia Society Board meeting Liz Carroll the CEO of the HS reported back to the Trustees on her meeting with Jan Barlow and Roger Evans.
39. It was alleged that Jan Barlow said that the Department of Health should wait for as long as possible before making any decisions as more people would have died and there would be less people to pay and fight for payment. This was recorded in the HS's Trustee meeting minutes dated 4 February 2015. It was also recorded that Liz Carroll did not comment on this point.
40. I asked Liz Carroll whether she would report this to MP Alistair Burt who was a health minister at the time. She did this and then also reported the conversation publically. This led to the MFT issuing a solicitor's letter stating that Liz Carroll must retract the statement or the Haemophilia Society would be facing legal action.
41. At the relevant time I wanted to fight and have our day in Court as Jan Barlow's comments would then let the world see what a nasty organisation the MFT was. However, the Chairman, Bernard Manson went over board and

capitulated to the demands of the Collective Board of the MFT and the legal advice. Liz Carroll was forced to not only give a public apology but to deny that Jan Barlow had ever said what she did.

42. This led me to resign my role on the HS board as a chap called [GRO-D] [GRO-D] sat on both the MFT board and was a Trustee of the HS. This meant that, as Trustee for the MFT he would have voted to take the HS to Court, causing probably closure of the organization. I found it incredible that anyone wanted him to stay on in these circumstances and I knew that I could not continue in my role as a Trustee, serving on a board with someone like that.
43. The HS never really wanted to face up to the contaminated Factor VIII tragedy. They gave Birchgrove money to advocate on our behalf but we were very much treated like the bastard at the family reunion and we were seen as an unfortunate episode in our history. He was not supportive and he went over the Board of Trustees. At this point I ran out of fight. Once they issued the apology and were done with the groveling I was so angry that we were portrayed like that in the papers. I said I could not serve on the same board as [GRO-D] because I cannot serve on a board of a Charity which wants to close down another Charity. I think he is still there to this day. Their behaviour was just so perverse and I was a Trustee at HS for just short of a year. We never got to the bottom of the reasons why this happened and it was just so wrong.
44. In December 2014 I was contacted by Liz and she told me that APPG were looking for someone who would go on record with a statement regarding the problems of being a Trustee at the MFT. Liz explained that [GRO-D] had told her of his problems and she already knew about mine so she asked if perhaps together we would be prepared to put on record what the issues were.
45. I agreed to go on record with my experiences and accusations but can only assume that [GRO-D] did not want to do so as on the day of the launch of the APPG findings along with the results of the survey I was the only one prepared to give a statement to MPs and members of the public at the meeting in Parliament.

## Campaigning

46. I have campaigned for over 30 years. During this time I have attended Parliament on numerous occasions, delivered a petition to Number 10 Downing Street, given evidence at the Archer Inquiry and been involved in Birchgrove (a group set out to help and advocate for those infected and affected by this awful tragedy). I have also seen numerous friends (too many to count) die and attended far too many funerals.
47. I met with David Cameron (whilst he was PM) and the Health Minister, Jane Ellison. The PM said that, along with Bloody Sunday and Hillsborough, the Contaminated Blood tragedy was something he wanted to sort out. He spoke about giving us something like what Scotland were getting at the time in terms of support payments (which was over double our income). He gave me his word that he would "*sort it*".
48. In advance of our meeting with the PM, I prepared a personal statement and a statement about the MFT. He listened and he was moved. Jane Ellison also attended and was almost moved to tears. I thought the meeting was successful. We had a cup of tea and a biscuit and David Cameron came across as a genuine man. As we walked out he asked me what I hoped to get out of this. I explained we shouldn't be given charity or benefits. We should be given enough finance to be able to live on and make every one of us comfortable. I know the Government cannot give me my health back but they could ensure my dignity and financial security. He understood, I thought he got it. I explained that before my health deteriorated as a result of the infection resulting from contaminated blood products I was a painter and decorator, I had a company and employed people. I wanted the Government to put me in a position I would have been in had I not been infected through contaminated blood. I was on £35k to £40k per annum but, at the time, I was receiving less than half of that.

49. Well over two months later the PM and the Health Minister did "*sort it*" and the DOH announced that instead of giving us a raise to bring us in line with Scotland (where haemophiliacs received £36k per annum), they were proposing to take money off us. I exchanged emails with Alastair telling him I might end up losing my house but he just told me that this is not what was intended. There was no grey area; I was going to have money taken away from me.
50. After the DOH announced the proposed cuts my friend (another co-infected haemophiliac) and I decided enough was enough and that we were sick and tired of being lied to by successive governments and politicians; we said that we needed to do something drastic to get the public's attention as to the appalling way our community was being treated. We decided to go on a treatment strike.
51. This was the final straw. Upon hearing this news another campaigner made contact with the Private Eye to write an article but I wanted a wider audience. We managed to contact an independent journalist who said she could only get the story into the Sunday Mirror as long as I was not anonymous; as they were only interested if they are able to put my face to the story. I had to speak with my family and my wife as it was a massive decision to become publicly open about this for the first time in so many years.
52. The article was published in the Sunday Mirror as a double page spread and the interview is available on YouTube. I do not know whether it made any difference but another two months past and the Government decided against the financial change. It shocks me that we had to go to those lengths. It was something I didn't want to do but had to. Desperate times called for desperate measures.
53. I feel disappointed that the PM went back on his word.
54. I first approached Westminster when Margaret Thatcher was the PM and many more local MPs and Health Ministers. I once attended a meeting of like-minded MPs and MP Normal Lamb who was a liberal health minister grabbed

me and said he just wanted to say that they were the only party with our best interests at heart. They wanted to put us in their manifesto to help the contaminated blood tragedy. He shook my hand. But not long after they formed the coalition they dropped us.

55. When I went to see MP Ben Gummer I thought it was the best meeting to date. He said he would help us, he said if the government could find the money to sort Equitable Life out they should morally find the money for the contaminated blood issue and told me that our cause was a prime example of why he got into politics. He appeared supportive of us. I went down to Westminster with my wife and daughter to watch the debate on whether they could award the extra money. He saw me and approached us to say sorry but they had put a three-line whip and he had to vote against us. I asked if he could go to the toilet and skip the vote he said it didn't work like that. There came a stage where we couldn't trust any politician.

56. MP Alastair Burt and MP Mike Penning said they could help us through the backdoor but were unable to compensate us as it was a legal issue.

57. I always said rightly or wrongly (rightly now) that the Government would never have paid us ex-gratia money through the MFT unless they thought they were culpable. They were paying us because they had something to pay for.

58. At the time the litigation case was a quick solution. They thought we would all be dead within a few years which is why the smallest amount of money was supposed to last indefinitely. Essentially, this is what they have been doing ever since; used a sticking plaster.

59. I am 61 years old now and I was diagnosed when I was 27. This is not over. The pain and trauma has been ongoing for all these years; compounded by the Government's approach. It was alluded that I suffer from Post Traumatic Stress Disorder but there is nothing 'Post' about it because it is ongoing. Each story is a tragic story and no one size fits all. My story has been compounded because I have always tried to advocate for people. I was a Trustee because

people like Roger Evans worried more about DOH targets than keeping people warm.

60. In approximately 1983/84 a bulletin of HS discussed 11 haemophiliacs in the US who died of AIDS related illnesses. It stated "*we think that the benefits outweigh the minuses and please continue to use Factor VIII as a safe product*". The HS was like gospel to mothers who would still inject their sons on that basis. Anyone who was worried ended up being falsely reassured and the HS never answered for this.

61. I still feel that they are waiting for us to drop dead. I cannot plan my financial future and I do not know whether I will get DLA/PIP every time I reapply. The Government is responsible for giving me the infection; yet I am the one having to jump through hoops to fill out the forms to receive any financial help whatsoever.

62. I have had to go through two humiliating and soul-destroying investigations this year alone with DLA to PUP and also capability of work assessment. Both times you will find in the forms which have almost identical questions and another layer of my dignity is stripped away. These are forms that I, and others in our community, feel we should not have to complete because the only reason we have to claim benefits (which we do reluctantly) is because NHS infected Factor VIII was given to us in the first place and provisions should have been made (and indeed it is still not too late for them to be made) for us not to have to go through this regular, degrading experience. I still have not heard back from either assessment so that adds extra stress to my life and makes it impossible for me to plan financially. I dread the post coming.

63. The stress of living with all this has affected the family and along with fighting for justice for more years than I care to remember, caused me to have a breakdown this year. I was admitted to a psychiatric ward for four weeks as I really have had enough of this life and do not know how much more I can take. It is important that the Inquiry understands and highlights the mental impact of not only the infections themselves but also the mental toll taken by the 40 year fight for justice and financial support.

64. At one point, getting a mortgage was impossible due to the inability to receive life insurance. A financial advisor Susan Daniels advised that we take out an interest only mortgage where the monthly payments over the term of the mortgage covered only the interest charged on the amount borrowed. This meant that the capital sum was then owed in full together with any fees or charges debited to your account at the end of the mortgage term. That meant we had to put aside money each month to pay off the capital sum at the end of the mortgage term. In turn, this meant that the amount we had saved regularly took me over the threshold for savings allowed whilst receiving benefits. Numerous investigations over the years from the DWP made me feel like a criminal. All this because I couldn't get a normal mortgage because I couldn't get life insurance, because of Factor VIII. I was investigated numerous times when reapplying for financial support which was awful. They were like the gestapo and even investigated my son's financial situation as he was residing at our family home at that time.

65. We know this Inquiry will mean business if people such as Roger Evans and Jan Barlow are called to give evidence. All we have heard so far are tragic stories. We need to hear from the people who made these stories happen in order for people to be held accountable. We need to know why these decisions were made. It is not about the money anymore as nobody has been held responsible for this tragedy.

**Statement of Truth**

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

Signed.....

GRO-C

**ALAN BURGESS**

Dated..... 18-10-2019 .....