Witness Name: Andrew Evans
Statement No: WITN1213013
Dated: February 2021

INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF ANDREW EVANS

I, Andrew Evans, will say as follows:- .

Section 1- Introduction

1. My name is Andrew Evans, DOB GRO-C 1977 and I live at GRO-C GRO-C Worcestershire, GRO-C with my wife, two children and stepchild.

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2 December 2020.

3. (Q1) I have held the following positions at The Macfarlane Trust ("the Trust")

Member of the Partnership Group (approx 1999 - 2012)

a. I came to be a member following a request/suggestion by Fran Dix the then social worker at the Trust, who I met at an event organised by The Haemophilia Society in collaboration with the Trust, for registrants of the Trust who were between the ages of 18 and 25.

Chair of the Partnership Group (approx 2006 - 2012)

b. As a member of the Partnership Group, ("the Group") when the position was vacated by another registrant, it was suggested that I put my name forth for the chairmanship. I was elected by default as nobody opposed me.

IT consultant and web developer (approx 2003 - 2012)

c. I had volunteered to assist a Staff member at Alliance House, with her college course on Java programming, where I first met the incoming CEO, Martin Harvey. I was deemed by him to be "in the know" when it came to IT and I was asked to look at some issues they were having with the office network. Having solved these, I was asked thereafter, by Martin on a regular basis, to manage the IT systems at Alliance House for the Trust. Additionally, I was asked by Martin Harvey if I could build the Trust a website, and within that create a "Bulletin Board" facility for registrants to communicate with each other. This I did. When the Skipton Fund was created, I was asked to build its website, and I did the same later for Caxton. I maintained all three websites for many years. I do not remember the exact year my IT and web relationship with the Alliance House bodies came to an end, but it was concurrent with Jan Barlow taking office as CEO in or about 2013 and she decided this role should be brought in house.

4. (Q2) As Chair of the Group, it was my responsibility to arrange and organise meetings of the Group on a quarterly basis. This would involve booking a facility (which usually included a conference room, a prepared lunch, tea/coffees, and hotel rooms for attendees who were travelling from a long distance), contracting an independent minute-taker (usually from a secretarial service), and preparing the agenda and delivering minutes once checked and verified by all members of the Group. My role during meetings was to facilitate discussion and collate points of action to be followed up. When I left in 2017 the chair was handed over to GRO-A and I didn't attend many meetings thereafter.

5. (Q3) I always reported to Martin Harvey, the then CEO of the Trust.

6. (Q4) As I recall I was only ever invited to attend two or three board meetings of the Trust, and only for those parts in which I was to speak to the Board on behalf of the Group. It's possible that the number of times was greater than three, but this is my recollection. It may be possible to find out from Board Meeting minutes.

7. (Q5) During my time with the Group, I was not remunerated. When I was Chair, I was paid travel expenses and provided with hotel accommodation where necessary when attending meetings. Accommodation was usually booked in advance. I was remunerated for my IT consultancy and web development work for the Trust/ Group during that time.

8. (Q6) I received no training or formal induction from the Trust as to its functions, aims and objectives. However, as a registrant of the Trust, I was aware of some of its functions and through the meetings of the Group, I became aware of the mechanics of the Trust's work, its objectives and restrictions in terms of its Trust Deed.

9. (Q7) I had an amicable relationship with the staff and CEO of the Trust. I worked with Peter Stevens on the Skipton website. We also worked on a Business plan together. My impression was that he was ok apart from the "old boys club" vibe he gave out. We had nothing more than a business relationship. The Trustees were not usually around and seemed to mainly communicate via telephone with the CEO.I don't think the Trustees could really understand what the beneficiaries were going through. I believe they were more concerned with keeping the Government on side rather than fulfilling their role. Many of the financial problems could have been resolved if they had asked for more money from the Government.

10. (Q7) As a registrant of the Trust and a point of contact for others, I was aware of the Trust's many failings. The general perception was that:
    a) Decisions surrounding financial support were arbitrary and not based upon monitorable standards, and were thus being applied unfairly;

b) The Trust was grossly underfunded and that the Board was not interested in approaching the Government for further funding; and;

c) it was perceived that there was a financial, social and communication disconnect between registrants and the Board of Trustees, who were seen as "looking down upon" those in their care.

11. (Q7) This last point was one of the reasons that I took on the role of The Group Chair, as I saw it as an opportunity to attempt to bridge that gap through diplomacy and keep the lines of communication open. In this respect I feel that I was partially successful. By the end of my time as Chair there was regular communication between the Board and the registrant body via The Group, including one or two instances of my being able to address the Board directly at their quarterly meetings. While this certainly didn't mean that all issues were resolved, I believe in some cases it did help. I might say that it was, at least, a step in the right direction.

12. (Q7) I don't recall any instances of difficulties that impacted the running of the Trust during Martin Harvey's tenure as CEO. The working relationship between registrants, staff and the Trustees facilitated by The Group was maintained as a worthwhile endeavour until Mr Harvey was replaced by Jan Barlow. At that point it appeared that the Trust's metaphorical doors were slammed shut to beneficiaries, from a communication perspective.

13. (Q8) I have nothing further to add to my second Witness statement **WITN1213009** at this time in respect of the aims and objectives of the Group.

14. (Q9) I refer to paragraphs 9- 12 above, which I believe answer this question.

15. (Q10) My replies to the listed questions are below:

    a. I refer to paragraph 3 above which answers this question.

    b. At any given time there were between 15 and 30 members of the Group, however there were many other registrants who communicated their concerns and received feedback via the Trust's web-based Bulletin Board forum.

c. The Trust staff present at the meetings varied. Martin Harvey usually attended during his time as CEO, accompanied by one or two other staff members. Initially the meetings were chaired by Peter Stevens, who was also Chair of the Board of Trustees. When replaced by GRO-A, as Chair of the Partnership Group the Board presence was intermittent, often with nobody from the Board in attendance. The remainder of the membership consisted of registrants (both infected and family members).

d. There was a crossover in membership between the Group and The Birchgrove Group. There was, on occasion, attendance at the Group meetings by a representative of the Haemophilia Society, usually the CEO, although from recollection this was infrequent. I recall it was a struggle to get anyone from the Haemophilia Society to attend due to the churn of CEOs.

e. In the main, I believe the Group met quarterly, although some meetings were skipped so they were occasionally six monthly.

16. (Q10) I don't recall exactly, the situation in September 2005 but it is possible that there were no distinct policies in place which left both staff and registrants in the dark about what could be applied for and awarded. There may have been a higher than usual rate of refusal of grants which prompted this discussion, but as I recall refusal was always an issue to one degree or another. The situation could have been improved by there being clear and transparent guidelines provided to registrants and staff and those guidelines being followed consistently.

17. (Q11) As I recall the DOH raised the issue of the level of reserves that the Trust was holding as it considered that it was higher than it deemed was appropriate or necessary, and suggested if the Trust did not agree to reduce the level of reserves this was a threat to future block funding allocations. If I remember correctly, the reserves were held at a level of about £3-4 million which was the estimated 12 months forward spend. The DOH considered that the reserve

should be halved. This was the first time that registrants became aware that reserves were held by the Trust at all. It was the view of the majority of registrants including myself, that the Trust ought not hold any reserves whilst registrants were being turned down for financial support; or at the least the reserves should be significantly reduced to say an estimated three month forward spend. It was felt that by not spending "to the wire" the Trust was effectively sending the message to Government that there was plenty of money for its needs. This was blatantly not the case. To compound this, the Trust only kept records of grants awarded, not of grants refused. Anyone looking over this paperwork might reasonably assume that supply met demand, whereas this was certainly not the case.

18. (Q12) I set out below my replies to the listed questions:

   a. Following the departure of Claudette Allen, no social worker was subsequently hired by the Trust. I don't know the exact reasoning behind the Trust's decision not to appoint a new social worker, but suspect that this was due to cost savings as Ms Allen was retained on some pay due to the circumstances of her departure GRO-A. I would suggest a staff member or Trustee would be in a better position to answer this question.

   b. A Social worker was absolutely an essential addition to the Trust's staffing. The social worker was the point of contact for most registrants, and their role was to facilitate/help those registrants to be able to make the most out of what the Trust could do for them in terms of grants and other services, such as benefits advice or signposting. Without a social worker in place, registrants were left to navigate the Trust's policies on their own or seek help from staff who were unfamiliar to them, had not been trained in a forward-facing role, and whose priorities may not be to help registrants but to keeping budgets under control. As a result, I believe grant applications and other assistance were adversely affected from an applicant's point of view.

c. From relatively early on the Board incorporated as part of its number two "user" trustees; that is two members of the registrant body. In theory these two roles would enable the registrant "experience" and interests to be fed back to the Board which ought to have assisted it in its decision-making. As time went on, however, it became clear that the functioning of the user trustees was hampered in effectiveness as the terms of board membership seemed to disallow these trustees from communicating with other registrants in order to feed back the wider perspective, and also that these trustees were instructed to behave in a manner which prioritised the Trust as an entity over and above the registrants it was set up to assist. In my view, the "user" trustee roles were created more to give an appearance of registrant involvement in the decision-making process rather than make it so. As a result, I consider that registrant's interests were not adequately represented on the Trust board.

19. (Q13) There were considerable concerns that the decision-making process on grant applications was arbitrary; that decisions whether grants were awarded very much depended upon the moods of the people making the decisions , as opposed to there being a standard set of qualifying criteria being followed in a consistent manner. As I recall, the Group suspected that no written qualifying criteria existed, and attempted to prove this by requesting a copy of them. From memory, no such document was ever forthcoming. In effect, application procedures and eligibility criteria were not only unclear, but indeed non-existent. **(What did the Group propose to rectify this?)**

20. (Q14) I don't recall this instance with any great clarity, but the issue was a recurring theme. The Group would ask for more grant applications to be approved, the Trust would counter with the "we have no money" argument. We would suggest that they demonstrate this in a funding application to the Government, and nothing would be done, and the argument would go round and round. It seemed that the Trust's leadership was afraid to press the Government too hard for increased funding lest it should find its funding further reduced in a "bite the hand that feeds you" scenario. I suspect that there was more to it than this, in that the governance of the Trust seemed to be specifically selected to

include those who would not rock the boat in terms of funding allocations. There was a pervasive view that if an applicant could afford "luxuries" such as Sky television then their application would be rejected. There were no set standards applied and no reasons provided as to why applications were rejected. Applicants were only told that "We cannot fund that at this time". Whilst there was access to an "appeal process" often it was the people who made the initial decision who decided the appeal which meant new evidence was needed for there to be any chance at all of a decision being overturned and that in reality it was unlikely any appeal would be successful .

21. (Q15) There was little or no medical expertise within the NSSC panel. There was, as I recall, a suggestion that Dr Mark Winter was consulted on applications where it was deemed a necessity to do so, but I have not been able to verify that this was ever the case. In truth, often decisions appeared to be based upon an applicant's current overall financial situation (means-testing) rather than any medical requirement, despite supporting evidence from registrants' medical practitioners. The NSSC did not deem it necessary to justify its decision-making, which was a constant cause for criticism from registrants along with the lack of a suitable appeals process or a functioning complaints procedure. I felt that the Trustees ignored medical facts that should have swayed decisions in beneficiaries' favour. As a system it wasn't intended to be means tested

22. (Q16) I'm afraid I don't recall enough about Mr Mishcon's dissertation questionnaire to identify any specific ethical issues but would assume that there were concerns around anonymity, and personal details being shared with others, given the stigma attached to the conditions the registrants were suffering from. These may not have been real issues, but the registrant community is damaged in nature and distrustful of anything that might compromise the meagre financial help they received from the Trust and of any personal information being disclosed.

23. (Q17) I don't believe that the Group was ever formally disbanded, however it ceased to meet shortly after Jan Barlow became CEO of the Trust in 2017 and EIBSS began to come online. The main means of communication for the Group

(the MFT Bulletin Board) was ordered to be closed by Ms Barlow, which made its functioning outside of physical meetings difficult. With the advent of EIBSS and other devolved national support schemes, the Trust's role became less important and the need for the Group as an entity to interface specifically with that organisation was diminished. The then chair of the Group, GRO-A may be able to advise further on the final meetings.

24. (Q18) As above. I don't recall the exact date of this, but it was shortly after Ms Barlow's appointment was made. The Bulletin Board was being used to organise petitions to the Trust, including petitions calling for the resignation of certain staff members and Trustees, and as a result I believe, being seen as a threat. It was closed shortly afterwards. Registrants attempted to recreate a forum outside of the control of the Trust which enjoyed some success.

25. (Q19) As far as I am aware the Group did not play any role in identifying new beneficiaries the Trust's beneficiary community was defined very early on and remained relatively unchanged throughout its existence. Very few people were identified after the early litigation. Upon occasion there was discovered a secondary infectee dubbed by the Trust as "infected intimates" who were encouraged to apply for financial assistance, but this as far as I am aware was the limit of new beneficiary discovery. The Trust's beneficiary numbers were limited and as they were all from the background of bleeding disorders were well accounted for from the outset, therefore in terms of finding new beneficiaries there was little to nothing that could be or needed to be done.

26. (Q20) My recall of the issue referred to in the meeting minutes is not clear, but it is apparent at the time this meeting took place there was appointed a small sub-group to determine the contemporary costs of living with HIV. I am unaware of the results of this sub-group's research. Generally, the focus of the Group over the years was to ensure that these extra costs were met and that the damaged community for which the Trust undertook a duty of care was adequately looked after, especially in times of extreme need or emergency. We felt the Group was initially a feedback exercise for the Trust and then as it developed, its focus was to try to hold the Trust accountable for its actions.

27. (Q21) I refer to paragraphs 5-6 of my second statement and paragraph 3 c above. I would add that I also undertook to maintain the Trust's IT network infrastructure, including overseeing a major overhaul when the Trust moved the location of its offices. The work was carried out by external contractors under my supervision, and I maintained the role of network manager for several years following this move, including one major server replacement and the deployment of the Trust's then new database software. I also maintained the websites for the Trust, the Skipton Fund and the Caxton Foundation. I undertook these roles to the best of my (limited) ability.

28. (Q22) Relations between the beneficiary community and senior staff varied considerably from person to person. As CEOs, Ann Hithersay and Martin Harvey were considered to be approachable by most and helpful to some. Ann was seen as someone who was sympathetic but had her hands tied and Martin was considered to be pragmatic. Some beneficiaries found difficulty in communicating with the senior management/the board by any means. I would like to think I helped to mediate on some of those occasions and offered my counsel to Martin Harvey to keep communication lines open.

29. (Q22) Relations between beneficiaries and the Board of Trustees remained virtually non-existent throughout my time dealing with the Trust. My attempts to combat this as Group chairman, namely, to invite Trustees to Group meetings in as many numbers and as frequently as possible, met with very limited success. In my view there was an intentional disconnect maintained by the Board in respect of the beneficiary community. I have speculated in this statement and elsewhere that the reason for this was that the Trustees viewed their role as working towards the maintenance of the Trust as an entity rather than the assistance of the people for whom it was created.

30. (Q23) I set out my replies to the listed questions below:

    a. I do not now recall the details, but I believe a hierarchical complaints procedure was not put into place until several months if not years after this meeting took place, and consisted of moving complaints upwards within the hierarchy of the Trust, step by step as necessary, up to Board level. As

I recall there was never any kind of external complaints component introduced. Some beneficiaries attempted to turn to the Charities Commission but were unsuccessful in obtaining help from that source. Therefore, in terms of complaints handling, the Trust was very much left to investigate itself and people were told to write to the Chairman.

b. I don't have a number for this unfortunately, but I recall I was aware there was a significant enough number to warrant a complaints procedure being deemed of enough importance to be discussed at length at Group meetings and within many online forums.

31. (Q24) Beneficiaries would come to meetings to air their grievances with the grant procedure. They felt safe in communicating with each other as they didn't have to provide names or feel they were putting their claim in jeopardy. I was asked on several occasions to advocate on behalf of beneficiaries whose grant applications had been turned down. As Group chairman I was probably the main port of call for those in need of assistance when the Trust had failed to help. My primary focus as chairman was to use the Group to facilitate communication between the Trust and beneficiaries and to highlight where this had apparently failed. When invited to attend Board meetings I would convey themes of apparent failure of policy and the resulting lack of assistance to beneficiaries directly to Trustees. The response was, in general, to "listen". I'm not convinced that these communications were ever taken seriously.

32. (Q25) As far as I am aware the beneficiaries were always kept at arm's length from any accountability by either the DOH or The Trust, with each claiming to absolve responsibility in favour of the other. According to the Trust, it was at the mercy of the funding allocation by the DOH which in effect meant that the DOH was its senior body dictating how it operated. When the issue was put directly to the DOH, it would state that the Trust was entirely autonomous, that the only role it undertook was to determine block funding and pay it, and that it could not interfere with the internal workings of the Trust as a charity. The Charities Commission was uninterested as it saw the Trust as an arm of Government. In

this way responsibility was deflected and no progress was ever made. We once met with Caroline Flint MP of the DOH in 2006 but this led to no improvements.

33. (Q26) The rejection of grant applications and the apparent policy towards the removal of many non-emergency grants caused enormous concern within the Group so that when it was revealed that large funding reserves were being held the almost unanimous view was that these should be fully depleted to demonstrate that the needs of the beneficiaries were not being met due to lack of funding. It was considered that by not doing this, the Trust was appearing to operate within its means and therefore did not need extra funding. It was also considered that any applications to increase the block funding allocation from the DOH would be seriously undermined by the substantial level of the reserves, and that this had likely been the case during the entire existence of the Trust. Trustees and staff didn't seem to understand that Government would not provide more money if there was £4m in reserve. It was very frustrating. They didn't want to rock the boat and had lost sight of the original purpose of the Trust.

34. (Q27) As part of an initiative by the Trust's chair Peter Stevens which was a result of continued pressure by the Group, this delegation was formed to deliver what Stevens called "the business case for increased funding". The idea was to present a case for increased funding in person with members of the delegation who were also registrants demonstrating how this funding was necessary from a "victim's" perspective. I was one such person. We met with Caroline Flint MP who was the responsible minister at the time. The aim was to attempt to pull on the heart strings of the DOH to obtain further funding but this was ultimately unsuccessful. My memory is too poor to recall precisely when this initiative began, but my guess is that it was approximately six months in advance of the delivery in November 2005.

35. (Q28) I do not consider the Trust was well run. In the context of the way in which it was set up, as a Charitable Trust funded by Government, the running was adequate to preserve that entity. However, I don't believe it ever really operated to full effectiveness for the benefit of those for whom it was created. The Trustees' bias was, I believe, always towards maintaining the status quo,

regardless of how woefully inadequate that was. We gained the impression some of the trustees thought the beneficiaries were getting free money and should be grateful for whatever was provided; they were subhuman and didn't need to be dealt with properly as the wrongs against them had been righted many times over. The legal structure of the Trust was wrong from the outset and effectively removed it from any form of accountability. This allowed it to operate ineffectively for the span of its existence and was never questioned by those who might have had the power to effect change. Complaints by registrants/beneficiaries when support was lacking had the force of smoke in the wind. It is my opinion that the Trust Deed (particularly clause 4 which determined the Objects of the Trust) was consistently ignored, particularly when it came to the assistance of the bereaved and family members, because in the board's view there simply wasn't enough money to fulfil it properly. The apathy shown by Trustees in pressing for this situation to be made clear to, and rectified by, Government is quite unforgivable.

36. I have nothing further to add at this time. Thank you for the opportunity to expand upon my experience with the Trust and Group.

Statement of Truth

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

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

Dated....28th February 2021....................