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Witness Name: GRO-B

Statement No: WITN3291001

Exhibits: N/A

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 7 December 2020.

I, GRO-B, will say as follows: -

Section 1: Introduction

Question 1 – Please set out your name, address, date of birth and any relevant professional qualifications relevant to the duties you discharged at the MFT.

1. I am GRO-B and my date of birth is GRO-B. My address is GRO-B.
GRO-B
2. I was nominated by the Haemophilia Society ('HS') to sit as a Trustee on the Macfarlane Trust ('MFT') Board. I have completed my Master of Science.

Question 2 - Please describe your employment history including the various roles and responsibilities that you have held throughout your career, as well as the dates.

3. I have held, and continue to hold, various positions which are somewhat relevant to the duties that I discharged at the MFT.
4. GRO-B

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[REDACTED] GRO-B [REDACTED]

5. In addition to the above, I have also held positions with various charities. Between 2012 and 2019, I was Trustee on the Board for the HS and between 2014 and 2019, I was Trustee on the Board for the MFT. I am currently sitting as Trustee on [REDACTED] GRO-B [REDACTED] and also hold strategic positions with the [REDACTED] GRO-B [REDACTED].

Question 3 - Please set out the positions you have held at or in connection with the MFT including with any committees, working parties or groups relevant to the Inquiry's Terms of Reference, and describe how you came to be appointed to those positions.

6. As mentioned above at Question 2, I sat as Trustee on the HS Board between 2012 and 2019 and MFT Board between 2014 and 2019. I was elected to the Board of the HS by registered members of the community, and I was nominated to the latter position (on the Board of the MFT) by the HS.
7. I did not hold any positions with any other committees, working parties or groups relevant to the Inquiry's Terms of Reference.
8. I was also briefly involved, as a 'back up' to another MFT Trustee, in the Infected Blood Reference Group ('**Reference Group**') that was set up by the Department of Health ('**DH**'). This was decided during a MFT Board meeting.

Question 4 - Please describe your role and responsibilities in the above positions.

9. My role and responsibility, in reference to my position as Trustee of the MFT and HS, was:
- to give input from a patient and research perspective (although, as I remember, patient and external intelligence carried little if any weight with regard to decision making metric).
 - act as part of the Board and provide input into decision making. [REDACTED] GRO-B [REDACTED]. As such, I tried to major on that in both organisations.

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10. As I observed, the MFT was a conduit between the DH and the beneficiary community, and its primary function was to disseminate annual funds in the most fair and equitable way possible to the infected and affected cohort. The Board's primary function was to preside over that process and the grants process, which was led by the Grants Committee and which I was not involved in.

Question 5 - What induction, training and information did you receive from the MFT as to its functions, aims and objectives?

11. I cannot recall receiving any induction, training and information from the MFT from the MFT as to its functions, aims and objectives.

Question 6 - How much time did you devote to the positions you held at the MFT? Please describe how your time was generally spent when discharging your role as a trustee of the MFT.

12. The function of the MFT had become quite limited by time I took up the role there. By limited, I mean that the MFT became more focussed on allocated resources directly to beneficiaries, as opposed to making available a lot of discretionary services. As such, my only real time commitment was to attend board meetings. Even this was impaired, as I have had health issues and significant professional commitments to consider.

Question 7 - Please set out your membership, past or present, of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

13. I cannot recall being a part of any other committees, associations, parties, societies or groups that are relevant to the Inquiry's Terms of Reference.

Question 8 - Please confirm whether you have provided evidence to, or have been involved in, any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. Please provide details of your involvement and copies of any statements or reports which you provided.

14. My parents were involved in litigation, on my behalf, when I was a child. However, I have no real knowledge or recollection of these, and do not possess any documents relating to this litigation either.

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Section 2: Establishment of the MFT**Appointment of Trustees**

Question 9 - Please provide a detailed description of the appointment process for the MFT and the exact composition of the board.

15. My appointment to the Board of the MFT was a discretionary option exercised by the HS. I am unable to recall what the appointment process for the MFT Board was or the exact composition of the Board.

Question 10 - What was the process for electing/re-electing trustees at the MFT? In particular, what involvement did (a) the DOH (or any other Government department) and (b) any other organisation or person have in this process? Did these matters change over time?

16. I am unable to recall anything else over and above the HS appointment I was party to. The only detail I can add, was that I was to be the last HS appointment to the MFT Board as my predecessor had waived the option to extend the term from the appointment procedure when it was set to expire.

Question 11 - How, if at all, were positions advertised?

17. I am unable to recall how positions were advertised as I was not involved in the recruitment of Trustees to the MFT Board.

Question 12 - Were there sufficient applicants of sufficient quality or did you struggle to appoint trustees?

18. I was not involved in the recruitment of Trustees to the MFT board and am therefore unable to answer this question. However, what I can say is that for what the MFT did in the end, it did not require a big board. It was actually very well populated for what it required.

Question 13 - Were you an appointed trustee for the Haemophilia Society? If so, please answer the following:

- a. ***How did you come to be put forward by the Haemophilia Society?***

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b. ***Did you receive any instructions from the Haemophilia Society on how to carry out your role?***

19. In answering Question 13a, I came to be put forward by the HS as its nominated Trustee-appointee to the MFT Board. The decision to nominate me was made during a HS Board meeting.

20. In answering Question 13b, I did not explicitly receive any instructions from the HS on how to carry out my role as a Trustee on the MFT Board, but it was implied that I should be going in there “like a bull looking for a red rag”.

Question 14 - How many trustees were appointed by the Government, how many by the Haemophilia Society and how many were ‘user’ trustees during your tenure at the MFT?

21. I am unable to remember how many trustees were appointed by the Government. With respect to the HS appointments, I cannot recall any other HS appointed trustees on the MFT Board during my tenure. My understanding was that the HS waived the right to continue their discretionary appointment right, with my appointment being the last possible under previous policy.

Question 15 - How long did each trustee serve on the board? Could a trustee be re elected? If so, how many times?

22. I believe that a Trustee could serve the board for a maximum of two terms. Each term was a duration of three years.

Question 16 - Were trustees remunerated for their work? Please include details of any policies on this, including policies for allowances/expenses.

23. Trustees were not remunerated for their work, except for travel expenses being recoverable.

Question 17 - Was there an overlap of trustees/directors between the AHOs? Please explain how this worked.

24. My recollection is that the Boards were kept separate.

Question 18 – The Inquiry understands that you were a Trustee of both the MFT and the Haemophilia Society at the same time. What were the advantages and disadvantages of this?

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25. Being a Trustee of both the MFT and HS was unpleasant for me. The HS was effectively acting on behalf of some disgruntled MFT beneficiaries. I got to see both sides of the fence and the reality was that both were groups of good people trying to do best for the communities they served.
26. As for the advantages, being on both Boards, I made it easier to see how there could have been a good strategic relationship between the MFT and HS (strategic and campaigning). However, this was unworkable due to the relationship between the two CEO's and some of the community members.
27. The MFT was run by a group of good people who all made different types of contributions from direct compassionate emotional support to having to make tough decisions regarding the dissemination of funds.

Question 19 - Minutes from a meeting of the Board of Trustees on 6 March 2015 [MACF000022_049], note that you were 'put in a very difficult position because of being on the boards of both MFT and the HS' in relation to alleged comments made by Roger Evans and Jan Barlow on 29 January 2015 as reported by the Haemophilia Society. In light of the above, please answer the following:

- a. **What was the response of the MFT board, particularly Roger Evans and Jan Barlow, after learning of the accusations made by the Haemophilia Society?**
 - b. **Why did you conclude that the letter referred to in the minutes was reflective of the Haemophilia Society's overall view?**
 - c. **How did your position as a board member for both MFT and the Haemophilia Society affect your response to the situation?**
 - d. **Did your relationship with either board change following the accusations? If yes, how so?**
28. In response to Question 19a, the MFT Board chose to support the CEO, Jan Barlow, as the alleged comments could not be substantiated and were being disseminated anyway. The comments were defamatory and could potentially harm the MFT and Jan's ability to operate in this and any future role, including reputational damage.
 29. In response to Question 19b, I don't recall. There was a lot of ill feeling toward the MFT and its CEO Jan. That ill feeling came from certain individuals within the HS due to the commentary that the HS was receiving from a few disgruntled members of the MFT, who were also members of the HS and appeared to be driving the agenda in a way that was not appropriate. I always did my best to maintain impartiality, despite being in communication with the both CEOs.

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30. In response to Question 19c, the situation was difficult for me because of the conflict between MFT and HS. I believe both organisations provided societal benefit, but there was a clear breakdown in relationship between both CEOs who I had a good relationship with.
31. In response to Question 19d, my relationship with either Board did not really change following the accusations. In fact, it made me more politically aware, not something I'm enamoured with as my intention of board membership is always to offer GRO-B GRO-B and not to be involved with "he said, she said" or tit-for-tat. I recall that I did offer my resignation to the HS, and subsequently the MFT, to alleviate any conflict. Both organisations rejected this.

Structure of the MFT

Question 20 - Please explain the extent to which the AHOs shared premises, staff and resources. What impact did this have on data sharing and confidentiality and how were such issues managed? How were documents and information stored by the relevant AHO? Was information shared across the AHOs? If so, were registrants aware of this?

32. Data governance and GDPR compliance was not, and is not, an area of expertise of mine. However, the staff in the office were highly professional and I believe they would have had appropriate firewalls and data storage facilities in place.

Question 21 - Why did the Caxton Foundation act as employer for all five AHOs?

33. I would assume structural efficiency, but this is not my area of expertise and I have no knowledge of why this was the case.

Question 22 - Please set out your recollection of the relationship between the different AHOs.

34. My recollection is that the MFT Board was pretty siloed. My understanding and exposure to the other charities was limited at best.

Question 23 - Please describe the working relationship between the trustees of the MFT and the senior management. Were you aware of any difficulties? If so, what were they, how did they impact on the running of the MFT and how, if at all, were they resolved?

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35. The relationship with staff was good. They are all nice people providing a function for below market rate because they are compassionate about the cause. It's a real shame these people are no longer able to support the community.
36. I know the staff were subjected to verbal and racial abuse from a very small number of beneficiaries, which was managed appropriately. For example, I can recall one colleague being abused over the phone and called "F***** n*****". This was wholly unacceptable behaviour.

Relationship with Government

Question 24 - To what extent was the MFT independent from the Government? How much oversight did the DOH (or any other Government department) have over the MFT? In particular, did the DOH have any involvement with and/or give any direction/guidance to the MFT (and if so, what?) as to:

- a. the composition of the board for the MFT.***
- b. the content of any policies adopted by the MFT;***
- c. how the MFT should discharge its responsibilities to the beneficiaries;***
- d. the kinds of applications the MFT should grant; and/or***
- e. the quantum of the grants/payments it should make?***

37. In response to Question 24a, I cannot recall.
38. In response to Question 24b, to my knowledge, the DH did not have any involvement with the content of any policies adopted by the MFT. However, the MFT policy was obviously informed by necessity to be able to navigate the UK's government funding routes.
39. In response to Question 24c, I cannot recall.
40. In response to Question 24d, I cannot recall.
41. In response to Question 24e, the relationship with Government was always managed carefully as they were obviously the source of funding. My involvement was limited overall, but when I went on to the Board I was expecting something different than what I saw. The MFT effectively operated as a department that equitably distributed funds to its assigned beneficiary community. This was independent of the DH and the majority of funds were passed through directly to beneficiaries. There was also a separate

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Grants Committee, that I was not part of, that administered applications for additional monies requested by beneficiaries (not all could be granted, due to finite funds).

Question 25 - Did you, or others within the MFT, raise any concerns and issues with the DOH about the funding, structure, organisation or running of the MFT, or about the involvement of the DOH, or about any other matter? If so, please explain what concerns and issues were raised. What was the response of the Department to those matters being raised?

42. I have no direct recollection of this, but the question of whether “the MFT should be a charity?” anymore was raised. My personal view was that it had narrowed its remit in accordance with what the majority of beneficiaries wanted (greater financial support). This was reflected in the website at the time.

Question 26 – What if any contact did the MFT have with the Department of Work and Pensions (‘DWP’)/its predecessors in relation to welfare benefits? In particular:

- a. **Were you aware of any beneficiaries having their benefits stopped as a result of the assistance they received from the AHOs?**
- b. **Did the MFT take any steps to prevent this happening? If so, what? If not, why not?**
- c. **Did the MFT raise this issue with the DWP/its predecessors and if so what was the response?**

43. I am unable to answer this question as I do not have any recollection.

Question 27 - Please describe the working relationship between the MFT and the DOH. Was there a particular point of contact? If so, who was that? Were you aware of any difficulties? If so, what were they, how did they impact on the running of the MFT and how, if at all, were they resolved?

44. Roger and Jan had the most interaction with the DH, and I believe other members of the Board had some interaction. My only interaction was fleeting when I attended a couple of meetings with the Reference Group.

Question 28 - What was the purpose of the Department of Health Reference Group? What information did it provide to the MFT? How did it impact the resignation of Roger Evans? You may wish to refer to [MACF0000027_154] when providing your response.

45. As I understand it, the Reference Group was established to understand the burden of blood borne viruses on patients. I remember that at the time of the Reference Group being established, it was clear that the MFT was finished. The flavour of the Reference Group was that it was there to talk about what was going to happen after the MFT was scrapped/closed. I thought it was dangerous that the discretion of having an arm's

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length charity organisation administering was going to be removed in favour of a central government department administering the funds. The reason being that if the DH ever decided to cease its funding to the MFT, the MFT had the option of becoming a more campaigning charity. However, an in-house government department could not exactly do this.

46. I cannot recall what information the Reference Group provided to the MFT, if any. Another MFT Trustee was the main member of the Reference Group. I was a 'back up' and only attended one or two meetings.
47. As for the impact of the Reference Group on Roger, in light of MACF0000025_154, I guess with the formation of the Reference Group (and perhaps some informal discussion), Roger knew the MFT was coming to an end. However, my recollection is that Roger had an accident and was quite badly injured and never came back. That is not reflected in the minutes.

Question 29 - As an appointee from the DOH, did you have a role within the Reference Group? If so, please provide details of your role. You may wish to refer to [MACF0000027_154] when providing your response.

48. I am unable to recall many details about this Reference Group as I only attended one or two meetings. However, it felt like a tenuous process in which decisions had already been made regarding the future of the MFT.

Question 30 - Why were there concerns regarding MFT's representation in the Reference Group? [MACF0000027_154]

49. I cannot recall why there were concerns regarding the MFT's representation on the Reference Group.

Section 3: Funding/finances of the MFT

Question 31 - Please set out the process by which the MFT received funding from the Government. Did this change over the time you were involved? If so, how? Were there problems with this process? If so, what were they and what were the consequences?

50. I am unable to answer these questions as matters relating to funding were dealt with by the Chair and CEO.

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Question 32 - What do you know about how the Government set the budget for the MFT? What input did you/the MFT have in this process? What input do you consider you should have had in this process? Did the Government take account of any representations made by the relevant AHO?

51. I am unable to answer these questions as matters relating to the budget were dealt with by the Chair and the CEO.
52. However, I do recall the sentiment being that under each review they would articulate that there was still unmet need, but the funding would remain the same. This reflected my view that the MFT was a strategic charity over a campaigning group.

Question 33 - What information, if any, did the MFT have about the beneficiary population and what was required to meet their needs? Where did this information come from? Was this information provided to the Government? If so, how and when? If not, why not?

53. A beneficiary survey was conducted before I arrived. I remember this because I would have loved to have ran this (it is what I do in various therapy areas). The results broadly said people wanted more money, which MFT had acted on by allocating more funds to regular payments and reducing services. I assume that the results of the survey would have been provided to the Government, however I do not know this for sure as I believe the survey was conducted before I was on the Board.
54. I still believe a comprehensive burden of illness study is necessary to truly understand the socioeconomic impact of the contaminated blood disaster.

Question 34 - Please set out as far as you can recall how much funding was provided at various times for the MFT.

55. I am unable to recall and cannot answer this question. This was dealt with by the CEO and Chairman.

Question 35 - Was the MFT informed of the budget allocation by the DOH at the same time each year? How did the timing of this notification impact the MFT's ability to plan the coming year's expenditure? You may wish to refer to [MACF0000022_033] when providing your response.

56. I am unable to recall and cannot answer this question. This was dealt with by the CEO and Chairman.

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Question 36 - In a MFT board meeting on 28 July 2014 [MACF0000026_086], it was noted that the DOH's allocation was 'less than was required'. Do you consider that the funding provided to the MFT by the Government was adequate? Please explain your reasoning.

57. There always seemed to be a remaining unmet need in some parts of the community, some of which may have been helped by additional funding and others that no amount of money could help.
58. I believe the overall answer is no. If government truly wanted that question answered, a public inquiry would have happened many years ago (previous inquiries had suggested that the level of funding was not adequate).

Question 37 - What opportunities or procedures were there for the MFT to seek additional monies and/or apply for top up monies from the Government as the financial year progressed? Was this ever done? If so, provide details.

59. The MFT played a strategic role and from what I saw, they were successful in continually getting their allocation from the DH, with a reserve that could be drawn on if the funding was stopped. This provided the organisation with the discretion to become more campaign based in focus if they were ever cut off by the DH. The NHS Business Services Authority does not give this safety net.

Question 38 - Were there annual or other regular reviews between the MFT and the DOH? If so, please provide details including the following:

- a. Did the reviews take the form of meetings? If so:**
- i. Who set the agenda for the meeting?**
 - ii. Who would attend the meetings?**
 - iii. Were any Trustees who did not attend able to contribute to the position to be put forward by the MFT and, if so, how?**
 - iv. What was discussed at the meetings?**
 - v. Were formal minutes, or any other written record, taken at the meetings? If so, by whom and who would be provided with copies?**
- b. If the reviews were conducted without meetings taking place, please provide full details of the process.**

60. I am unable to answer this question as this was outside the scope of my role as Trustee.

Question 39 - Did the MFT have ad hoc meetings with the DOH? If so:

- a. How were these meetings arranged? Could the MFT call for such meetings?**
- b. Who set the agenda for these meetings?**

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- c. *Please describe any such meetings you know took place, including dates where possible.*
- d. *Who would attend these meetings?*
- e. *Were the Trustees who did not attend able to contribute to the position to be put forward by the MFT and, if so, how?*
- f. *Were formal minutes, or any other written record, taken at the meetings? If so, by whom and who would be provided with copies?*

61. I am unable to answer this question as this was outside the scope of my role as Trustee.

Question 40 - Did the relevant AHO have any other streams or sources of funding/income other than that provided by Government during your tenure? If so, where did this come from, how much was it, and how was it managed/spent by the relevant AHO?

62. I am unable to recall, and this was not my area of expertise.

Financial management/governance

Question 41 - Were budgets/ budget forecasts made by the MFT prior to the start of the financial year? If so, how were the needs of the beneficiary population forecast? If not, why not?

63. I have no recollection of whether the budgets/budget forecasts were made by the MFT prior to the start of the financial year. However, I do know that the DH was made aware of the unmet need in the beneficiary community. I have no recollection of how they were made aware, however, I think, there may have been a newsletter.

Question 42 - What was the impact on the MFT of spikes in applications and the amounts of funding being applied for?

64. Again this was not within the scope of my role, but like any other organisation, the MFT operated within a finite budget and allocated as equitably as possible. Applications for grants were dealt with by the Grants Committee.

Question 43 - Was the board flexible with its budget allocation? For example if there was an underspend in the regular payments budget, could this be allocated elsewhere? You may also wish to refer to [MACF0000022_080] when providing your answer.

65. I cannot recall whether the Board was flexible with its budget allocation, and this was not within the scope of my role as Trustee.

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Question 44 - Was the MFT underfunded in your view? If so, what was the impact on the MFT?

66. Yes, in my view the MFT was underfunded as noted also in my response to Question 36. However, the extent to which it was underfunded was difficult for anyone to understand [REDACTED] GRO-B

[REDACTED] GRO-B

[REDACTED] GRO-B The human capital impact has never truly been captured.

Question 45 - Who decided on the level of reserves the MFT should maintain? Were you involved in those decisions? What was the justification for the level of reserves?

67. The MFT held reserves when I arrived and my understanding was that they were in part using it to supplement regular payments, issue grants and to have some security if DH paused, stopped or reduced funding. To me the financial strategy seemed prudent.

Question 46 - Did the level of reserves impede or otherwise have an impact on the MFT's negotiations with the Government for increased funding?

68. I cannot recall whether the level of reserves impeded or otherwise had an impact on the MFT's negotiations with the Government for increased funding, and this was not within the scope of my role as Trustee.

Question 47 - What, if any, steps did the MFT take to cut its operational costs so as to maximise the monies available for beneficiaries?

69. I cannot recall what, if any, steps the MFT took to cut its operational costs as to maximise the monies available for beneficiaries, and this was not within the scope of my role as Trustee. I believe this was done before my appointment as Trustee.

Question 48 - What, if any, steps did the MFT take to ensure that the salaries it paid its staff were proportionate and/or commensurate with the charitable sector?

70. I was not involved in recruitment, but the salaries looked within the boundaries of what I would expect. They were significantly below what the staff would receive were they providing similar expertise in the private/commercial sector.

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Section 4: Identifying beneficiaries for the MFT

Question 49 - Whose responsibility was it to identify potential beneficiaries for the MFT?

71. I have no recollection about whose responsibility it was to identify potential beneficiaries for the MFT, and this was outside the scope of my role as Trustee.

Question 50 - How were potential beneficiaries of the MFT identified?

72. I have no recollection regarding how potential beneficiaries of the MFT were identified, and this was outside the scope of my role as Trustee.

Question 51 - What, if any, steps were taken by the MFT to advertise its existence and/or raise awareness of its work?

73. I have no recollection of what steps were taken by the MFT to advertise its existence and/or raise awareness of its work, and this was outside of my role as Trustee.
However, I will add that this was an organisation that represented a group of people, who, for the best part, wanted to remain anonymous.

Question 52 - Do you consider that more should have been done (and, if so, what and by whom) to reach people who might be eligible for assistance?

74. It is difficult to reach such a niche cohort, especially as the majority of, if not all, of MFT beneficiaries would/should have been registered many years earlier. I was unaware of people being overlooked.

Section 5: Eligibility for the MFT

Question 53 - Who set the eligibility requirements (i.e. what an applicant had to show in order to be accepted as eligible) for the MFT?

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75. I cannot recall who set the eligibility requirements for the MFT, and this was outside the scope of my role as Trustee.

Question 54 - Were they written down? If so:

- a. **Was the written policy publicly available or otherwise accessible to applicants? If not, why not?**
- b. **Where or how could individuals access it?**
- c. **Did the Government have a view as to the publication of policies about the eligibility criteria? If so, what was it?**

76. I cannot recall and this was outside the scope of my role as Trustee.

Question 55 - Were you, in your role, consulted about the eligibility requirements or otherwise involved in formulating them? If so, please provide details.

77. I am unable to answer this question as I have no recollection.

Question 56 - What were the eligibility requirements? Did they change over time and, if so, how? For example, were there periodic reviews of such requirements?

78. I cannot recall and this was outside the scope of my role as Trustee.

Question 57 - Were there discrepancies or differences in the eligibility requirements between the MFT and the different AHOs? If so, what were they and were they justified in your view? If not, did you raise this with anyone, and if so, who and when? What was the response?

79. I cannot recall and this was outside the scope of my role as Trustee.

Question 58 - Was a medical opinion required to determine eligibility? If so, from whom and what issues was it expected to address? How were applicants alerted to the requirements for medical evidence?

80. I cannot recall and this was outside the scope of my role as Trustee.

Question 59 - Who set the procedural requirements an applicant needed to satisfy before being accepted as eligible as a beneficiary for the MFT?

81. I cannot recall and this was outside the scope of my role as Trustee.

Question 60 - What were the procedural requirements for establishing eligibility? Did they change over time and, if so, how? In answering this question please address the following:

- a. **Was there a burden of proof on the applicant and, if so, what was the standard and how did it operate?**
- b. **What kind of evidence or information did an applicant have to provide?**

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- c. *Was there a requirement for an applicant to have evidence of receipt of blood/blood products in their medical records (even in circumstances where the NHS had lost/destroyed the relevant medical records or they were otherwise unavailable through no fault of the applicant)? If so, why?*
- d. *What other documentary evidence was required?*
- e. *How were the requirements for evidence and any policies on the burden and standard of proof brought to the attention of applicants before they made their applications?*

82. I cannot recall and this was outside the scope of my role as Trustee.

Question 61 - Were these procedural requirements written down and publicly available? If so, where were they available and how could they be accessed by applicants? If not, why not?

83. I cannot recall and this was outside the scope of my role as Trustee.

Question 62 - Were there discrepancies or differences in the procedural criteria between the different AHOs? If so, what were they and were these justified in your view? If not, did you raise this with anyone and, if so, who and when? What was the response?

84. I cannot recall and this was outside the scope of my role as Trustee.

Question 63 - Were the eligibility requirements (both substantive and procedural) kept under review by the board of the MFT? If so, how often? If not, why not?

85. I am unable to answer as I cannot recall whether the eligibility requirements were kept under review by the Board of the MFT.

Question 64 - Who determined whether a person met the eligibility requirements to become a beneficiary for the MFT?

86. I cannot recall and this was outside the scope of my role as Trustee.

Question 65 - Were you aware of any concerns about or dissatisfaction with either the substantive or the procedural eligibility requirements for the MFT? If so, what were these and what did you/the board do in response?

87. I cannot recall and this was outside the scope of my role as Trustee.

Question 66 - Please describe the process (if any) for seeking a review of, or appealing against, or complaining about, a determination that an applicant did not meet the eligibility criteria for the MFT. Relevant matters include:

- a. *Any right to give evidence or make representations in person;*
- b. *Whether a representative was permitted to accompany the applicant;*
- c. *The standard of review or appeal applied;*

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- d. *The criteria for members of review or appeal panels, including whether the original decision-maker was permitted to be present or make the decision;*
- f. *The extent to which written reasons were provided; and*
- g. *Any time limits or fees for the bringing of a review or appeal.*

88. I cannot recall and this was outside the scope of my role as Trustee.

Section 6: Decisions on substantive applications within the MFT

The process

Question 67 - Please explain who made decisions on applications for the MFT and how this changed from your appointment in 2014 until the end of your service. In particular please explain:

- a. *When, if ever, staff employed by the MFT were able to determine applications, and which staff did so.*
- b. *Which committees were formed for the determination of applications, how they were formed, who was chosen (and why) to sit on them, how often they met, who they reported to and the process they adopted for the determination of applications.*
- c. *Which (if any) decisions on individual applications were made at board level and why?*

89. I take it that this series of questions, where it references 'applications', is referring to applications for grants as opposed to applications to become beneficiaries.

90. In response to Question 67a, I cannot recall, if ever, staff employed by the MFT were able to determine applications, and which staff did so.

91. In response to Question 67b and 67c, the Grants Committee determined applications. I remember that Patrick Spellman chaired the Grants Committee. I cannot recall how the Committee was formed, who was chosen (and why) to sit on it, or how often it met. I am aware that routine cases were not referred to the Board, but some exceptional cases were. For example, some questionable loans were given to some beneficiaries early in the day that were legacy, and came up at board meetings. I recall one matter where a beneficiary had bought their house with a 0% interest loan, and did not want to pay the loan back. I recall they were quite critical of the MFT. There was another application that came to the Board which related to a beneficiary wanting to start a soap business.

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Question 68 - Please explain whether the MFT developed written or unwritten policies for the determination of applications. If so:

- a. **Who developed these? Were they publicly available? If so, where were they available?**
- b. **Was any expert (medical or other) advice sought to inform those policies? If so, what advice? Please give examples.**
- c. **Were the views of the beneficiary community taken into account when setting the policies? If so, how was this achieved? Please give examples.**
- d. **Please describe the policies.**

92. I cannot recall and this was outside the scope of my role as Trustee. However, I do know that the policies were fair and equitable.

Question 69 - What were the procedural requirements an applicant had to satisfy when making an application for a grant? Who set these requirements? In particular:

- a. **What was the burden and standard of proof for such applications?**
- b. **Were the procedural requirements reviewed? If so, by whom and how often? What were the outcomes of those reviews?**
- c. **Were you aware of beneficiaries who were unable to satisfy the procedural requirements such as providing supporting documentation? What if any adjustments or provision were made for determining such applications?**

93. I cannot recall and this was outside the scope of my role as Trustee. Also, I did not sit on the Grants Committee.

94. However, I am aware that a formal Grants Committee was required to remove any informality and 'loose' processes that may have previously been administered. When Jan came in, she put in equitable distribution processes.

Question 70 - What proportion of applications were granted (wholly or in part) and what proportion were refused?

95. I cannot recall and this was outside the scope of my role as Trustee. Also, I did not sit on the Grants Committee.

Question 71 - Were reasons for refusing an application provided to an unsuccessful applicant?

96. I cannot recall and this was outside the scope of my role as Trustee. Also, I did not sit on the Grants Committee.

Question 72 - Was there a procedure in place to consider applications made on an urgent basis? If so, what was that procedure? If not, why not?

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97. I cannot recall and this was outside the scope of my role as Trustee. Also, I did not sit on the Grants Committee.

Question 73 - What practical support or assistance was given to applicants to help them in making applications?

98. I cannot recall and this was outside the scope of my role as Trustee. Also, I did not sit on the Grants Committee.

Question 74. Please set out the number of beneficiaries/applicants assisted by the MFT during the time you worked there.

99. I cannot recall and this was outside the scope of my role as Trustee. Also, I did not sit on the Grants Committee.

Question 75 - Please describe:

- a. **What regular payments were made to beneficiaries and how they were assessed/quantified.**
- b. **What lump sum payments were made to beneficiaries and how they were assessed/quantified.**
- c. **What payments or grants were made for specific expenses or items and how they were assessed/quantified.**

100. I cannot recall and this was outside the scope of my role as Trustee.

Question 76 - Did the success or otherwise of an application depend on the number of applications made per year or was each application considered on its merits, irrespective of the overall demand on the relevant fund?

101. I cannot recall and this was outside the scope of my role as Trustee.

Question 77 - What was the percentage of applications that were successful each year?

102. I cannot recall and this was outside the scope of my role as Trustee.

Question 78 - Did the Trust consider the amount of money previously given to an applicant from (i) the MFT, and/or (ii) other AHO's, and/or income from benefits when determining each application? If so, why?

103. I cannot recall and this was outside the scope of my role as Trustee.

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Question 79 - Were the grants means tested? If so, why? What were the income brackets applied? Were the income brackets published? If so, where and how could the beneficiaries access this information? Were the income brackets kept under review? If so, how and in what intervals?

104. I cannot recall and this was outside the scope of my role as Trustee.

Question 80 - Please provide your view on the consistency and fairness of decision making by the MFT when assessing applications.

105. The process seemed to be unbiased and fixed to ensure fair, responsible and equitable allocation of limited funds.

Question 81 – Why did you not become a member of the Grants Committee? Why was it decided to replace the National Support Services Committee? [MACF0000026_057].

106. I did not become a member of the Grants Committee due to it not being my area of expertise, time constraints and my own health considerations. I cannot recall why it was decided to replace the National Support Services Committee.

Loans made by the MFT

Question 82 - Please describe how the decision to make loans and advances rather than give grants came about as a matter of policy, and how the Board considered this was consistent with the MFT's charitable purpose.

107. I cannot recall and this was outside the scope of my role as Trustee.

Question 83- Please describe the different types of loans and advances provided by the MFT to beneficiaries.

108. I cannot recall and this was outside the scope of my role as Trustee. However, as I have mentioned above, I do recall legacy outstanding loans from the previous MFT management structure. On at least one occasion, a 0% loan was given to an individual who used it to purchase a home.

Question 84 - Were loans or awards made contingent on beneficiaries accepting the services of a financial advisor? If so, what was the criteria for such a condition to apply?

109. I cannot recall and this was outside the scope of my role as Trustee.

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Question 85 – Please describe any role you had in approving loans and/or advances made by the MFT to beneficiaries.

110. My role in approving loans and/or advances made by the MFT to beneficiaries was limited, but I do recall some discussion on outstanding loans that had been made and not repaid. My recollection was that these issues were a legacy from the previous Managing Director and allocation framework. I have referred to this above in my statement also.

Question 86 - Please describe the criteria used to select recipients for the different types of loans made by the MFT to beneficiaries, and confirm who drafted those criteria.

111. I cannot recall and this was outside the scope of my role as Trustee. However, I do recall that the criteria required the applicant to substantiate medical need.

Question 87 - Please confirm whether the MFT sought legal advice with regard to the loans made by the Trust. If so, what did that advice say (please note that legal professional privilege has been waived by the Macfarlane Trust)? Did you agree with that advice? Did the Macfarlane Trust act in accordance with that advice?

112. I cannot recall and this was outside the scope of my role as Trustee.

Non-financial support

Question 88 - What, if any, non-financial support was available to eligible beneficiaries of the MFT? Was the availability of non-financial support made known to the potential beneficiaries, and if so how?

113. I cannot recall and this was outside the scope of my role as Trustee.

Section 7: Complaints, reviews and appeals

Question 89 - Was there an appeal procedure for the MFT? If so, what was it and how did it operate? Who determined the appeal and were they the same staff who made the original decision? In particular:

- a. **Was there a right to give evidence or make representations in person;**
- b. **Was a representative permitted to accompany the applicant;**
- c. **What was the standard of review or appeal applied;**
- d. **Who heard appeals, and was the original decision-maker was permitted to be present or make the decision;**
- e. **Were written reasons provided; and**
- f. **Were there any time limits or fees for the bringing of a review or appeal.**

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114. I cannot recall and this was outside the scope of my role as Trustee.

Question 90 - How common was it for decisions to be appealed? How many appeals were you aware of being launched during your tenure? How frequently did appeals succeed?

115. I cannot recall and this was outside the scope of my role as Trustee.

Question 91 - Was there a complaints process? If so how did it operate?

116. I cannot recall and this was outside the scope of my role as Trustee.

Question 92 - How common was it for the MFT to receive complaints? How many complaints were you aware of being made? How frequently were complaints upheld?

117. I cannot recall and this was outside the scope of my role as Trustee.

Question 93 - What information was provided to beneficiaries about the appeal and complaints procedure?

118. I cannot recall and this was outside the scope of my role as Trustee.

Section 8: Engagement with the beneficiary community

Question 94 - What steps did the MFT take to engage with and understand their beneficiary community?

119. A survey of the beneficiary community was conducted before I arrived which supported the strategy of streamlining services and prioritising resources allocation in form of regular payments. After this, my understanding was that applications were submitted to DH for funding whilst informing them more was needed to meet the unmet needs of the beneficiary community.

Question 95 - Did the MFT set up any groups or meetings involving the beneficiary community? If so:

- a. **What was the purpose of the groups/meetings?**
- b. **How often did they take place?**
- c. **Who set the agenda?**
- d. **Who attended the meetings and how were the beneficiaries selected for these meetings?**

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- d. *What impact, if any, did these have on the way the MFT operated?*
- e. *Were there any problems encountered in the running of the group/meeting and how were they handled?*

120. The groups were reduced and the MFT beneficiary chat room was stopped to my memory. There are members of the community that make it difficult/impossible to hold constructive conversation. Myself and my wife have been subject to abusive interaction with small sections of the community (both before and after my appointment to the MFT). I have discussed this further below at Question 113 of my statement.

Question 96 - What was the relationship between the senior management/board of the MFT and the beneficiary community? Could this have been improved in your view? What steps did you take to improve the relationships?

121. I personally tried to approach the community directly on an unofficial chat room and was just met with aggression and anger, because I didn't choose to abruptly walk away from the charity like another trustee.

122. My personal integrity was questioned (ie, that I paid for a family holiday with MFT grant, which is wholly untrue) and the members were suggesting divulging my status in the public domain (which has, by proxy, been done in this Inquiry anyway).

123. Given the aggression I was met with (despite being new on the MFT board at the time) I was unable to engage with community members in the public domain. This restricted my ability to engage.

Section 9: Relationships with other organizations

Question 97 - What involvement or interactions did the MFT have with the Haemophilia Society?

124. There was limited interaction, particular after the incident between the CEOs of both MFT and HS.

Question 98 - Please describe the working relationship between the MFT and the Haemophilia Society. Were you aware of any difficulties? If so, what were they, how did they impact on the running of the the MFT and how if at all, were they resolved?

125. The CEO's of the HS and MFT had an unworkable relationship. I made failed efforts to bridge the gap, like, for example, e-mailing both CEO's to urge them to work together on the reference group.

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Question 99 - During your tenure with the MFT, were there any directors/trustees who were also trustees of the Haemophilia Society? If so, please give details. Did this have an impact on the relationship between the two organisations? Please give details.

126. During my tenure with the MFT, I was the only Trustee who sat on both HS and MFT Boards.

Question 100 - What involvement or interactions did the relevant AHO have with the UK Haemophilia Centre Directors Organisation?

127. I understand that there was very little involvement or interaction with the UK Haemophilia Centre Directors Organisations, however this was outside the scope of my role as Trustee.

Question 101 - Please describe the working relationship between the relevant AHO and the UK Haemophilia Centre Directors Organisation. Were you aware of any difficulties? If so, what were they, how did they impact on the running of the relevant AHO and how if at all, were they resolved?

128. I do not recall there being any relationship between these two organisations.

Question 102 - Please list any particular clinicians you were in regular contact with during your work with the MFT.

129. Dr Vanessa Marlew was on the Board of Trustees. She is a very good person, with integrity, GRO-B.

Section 10: Reform of MFT

Question 103 - Please provide details of any consultation or reform process you were involved in, in respect of the MFT.

130. I believe that the MFT had already been reformed (that is, by prioritising the use of funds to increase regular payments to beneficiaries) when I arrived and it was wound down after a while.

Question 104 - What was your view of the changes made to the MFT as a result of the Archer Inquiry?

131. The changes made were progressive, however, within the limits of the resources available from Government.

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Question 105 - What impact, if any, did the conclusion of the APPG Report in January 2015 have on the operation of the MFT? [MACF0000045_002]

132. I am unable to recall the impact of the APPG Report on the operation of the MFT.

Question 106 - In the MFT Annual Financial Report for the year ending 31 March 2015 [MACF0000045_002], it notes the Trust's response to the APPG Report, commenting on 'the financial constraints - which give rise to much of the criticism about the way the organisations operate'. Do you agree or disagree that the financial restraints of the Trust generated the most criticism? Please assess what caused these financial constraints during your tenure as MFT Trustee.

133. The resource allocation from the DH limited the MFT's ability to meet all known unmet needs within the beneficiary community, but I believe the MFT allocated the resources they had fairly and equitably.

Question 107 - The Annual Financial Report [MACF0000045_002] also notes that Trustees 'were interested to see that the report revealed a perception amongst many that the Alliance House organisations have what amounts to a "cosy" relationship with the Department of Health'. Do you think this is a fair assessment of the relationship between the MFT and the DOH?

134. I do not agree that it was appropriate to refer to the relationship between the AHOs and DH as being 'cosy'. This implies that the relationship was conducted in a manner that was inappropriate in some way. Strategic organisations need to have sustainable relationships with appropriate government departments, especially when they are the sole/major provider of funds for the support they administer to their community. I would be more concerned if the MFT did not share a good relationship with the DH. It needed to be able to engage with the DH, which is key to the longitudinal security of maintaining funding. I would be concerned if the MFT and DH had a confrontational relationship.

135. There is clear dichotomy between strategic and campaigning charities. The MFT was the former.

Question 108 - What concerns, if any, did you or the MFT have about the 2016/2017 reforms?

136. I am unable to recall as I was largely unable to contribute at this point due to health, work commitment and uncertainty over the future of the organisation. I do know that at this point in time there was already some uncertainty around the future of the MFT.

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Question 109 - Did the DOH address the issues raised in the joint response sent by the Alliance House organisations in response to the January 2016 consultation document and if so, how and when?

137. I have no recollection of this and was not involved.

Question 110 - Did you raise any objection to the changes suggested or request additional time to consider the impact? If so, what was the response?

138. As mentioned above, I have no recollection of the changes and was not involved in the process.

Question 111 - Did you have a role in the transfer of power to the Business Services Authority? If yes, what exactly? [MACF000027_147]

139. No, I did not have a role in the transfer of power to the Business Services Authority

Question 112 - Regarding the transfer to the new schemes?

a. How was information shared between the MFT and the new schemes?

b. What information was shared between the MFT and the new schemes?

c. What were beneficiaries told?

d. Were you aware of any problems with the transfer?

140. As mentioned above, I was not involved with the transfer to the new scheme and have no knowledge of this.

Section 11: Other

Question 113 - Do you consider that the MFT was well run? Do you consider that it achieved its aims and objectives? Were there difficulties or shortcomings in the way in which the MFT operated or in its dealings with beneficiaries and applicants for assistance?

141. The MFT was staffed by individuals who, as I have mentioned, were compassionate individuals who wanted to help the beneficiary community. I would also describe myself in those terms. To my knowledge, both Roger and Jan did a good job by putting in requests for funding each year and informing the DH that there were still unmet needs within the beneficiary community.

142. The MFT had a difficult role in serving a community that had fragmented needs. It was difficult to gauge the needs as any direct interaction with the community meant feedback was slanted to those who were most vocal in expressing their views – that

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did not necessarily reflect those who had the most needs, or the greatest need for assistance. The criticisms came from a small number of people and did not, in my opinion, reflect the views of the overall beneficiary community. This meant that there was no genuine balanced representation aside from the limited survey.

143. For the best part, my understanding was that the majority of beneficiaries got on with their lives, but felt they had received insufficient financial support. Hence the MFT prioritising higher fixed payments and reducing services.
144. The support the MFT provided within its budget constraints in my opinion was equitable and fair, having regard for the limited funds at the MFT's disposal.
145. In terms of shortcomings, as a GRO-B, it is my opinion that we never robustly assessed the unmet needs of the cohort. This was my personal view, and I made this clear. However, I know the MFT did try and do this before I joined; with the survey it undertook. On reflection, I feel that there could have been more active dialogue between the MFT and DH, with the latter advising what metrics it needed to better see the level of support that was necessary. However, this is political.
146. There is also the question of whether the MFT should have been a charity. Although, in my view, the alternative of it being an in-house government department meant, as I mentioned before, that if the DH ever cut funding, it was unlikely an internal department would be campaigning the government for more funding. The MFT, with its status as a charity, was in a better position to raise concerns regarding funding with DH, if the DH ever cut funding.
147. I recall that when I was first appointed to the MFT Board, I really wanted to engage with the beneficiary community and did so using a private chat forum on a website on which affected beneficiaries could have discussions. I even gave the beneficiaries on the forum my phone number to open up communication and better understand their needs. I was simply seeking to make myself available to them, so they could convey their views to me directly if they wished, to assist me in outing those views to the MFT Board.
148. However, I was incredibly disappointed and disheartened to see that, in a small number of responses, I was lambasted and abused in writing with wild and baseless accusations made against me. They said I wanted to use the MFT money to further my career, and also made allegations I had used MFT funds to go on a holiday with my

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family (someone looked up my social media, saw pictures of a holiday, and insinuated that I must have used MFT funds for that – completely ignoring the fact that I have a career and income of my own from my work). There was absolutely no substance to these wild accusations. There was also a narrative that I was young and ill informed, whereas a lot of the beneficiaries had become unwell before I was even born. This was all disturbing because I have never depended financially on the MFT funding and was only there on the MFT Board as a public service to others and to find opportunities to do better for the community. I found this reaction very unfortunate, as I had only been seeking to help and be open to direct communication with the beneficiary community. I have copies of the messages on this chat forum which I can provide to the Inquiry if required.

149. All in all, I would like to say that the majority of aggressive campaigning came from a minority who had sadly and understandably been deeply psychologically impacted by this disaster or who had taken out loans from the MFT and didn't want to pay them back (ie for house purchases or starting business's). Their views were not reflective of the wider beneficiary community.

Question 114 - Please provide any other information and or views you may have that is relevant to our Terms of Reference.

150. I have nothing further to add beyond what I have said in answer to the previous question.

Statement of Truth

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

Signed

GRO-B

Dated 26th May 2021