

Witness Name: Tracey Price

Statement No. WITN2533002

Dated: 24th November 2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF TRACEY PRICE (NEE MORGAN)

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 3 December 2020. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Tracey Price (nee Morgan) will say as follows:-

Section 1: Introduction

1) Please set out your name, address, date of birth and any relevant professional qualifications relevant to the duties you discharged at the relevant Alliance House Organisation 1 ('AHO').

1. My name is Tracey Price and my address and date of birth are known to the Inquiry. I make this statement to describe my involvement as a user Trustee for the MacFarlane Trust insofar as it is relevant to the Inquiry's Terms of Reference.

2) Please set out the positions you held at 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.

2. I was a user Trustee for the Macfarlane Trust (MFT) appointed by the Haemophilia Society from January 2003 to December 2004. I sat on the main Board of Trustees and was part of the Working Group regarding Grants and Regular pay.

3) Please describe your role and responsibilities in the above positions.

3. My role was to attend Board meetings and the Working Group meetings. I offered my views, questioned decisions, and also helped make decisions on budgets, grants etc. I did not have any dealings with the day to day running of the office or its staff.

4) What did you understand the aims and objectives of the MFT to be? What induction, training and information did you receive from the MFT as to its functions, aims and objectives?

4. I understood the purpose of the Macfarlane Trust to be a vehicle to deliver financial assistance to people who contracted HIV from blood products, by way of regular payments and grants issued by the office, and larger grants administered by the Board.
5. I was interviewed for the position by Anne Hithersay and Peter Stevens and offered the position just before Christmas 2002. I did not receive any training or an induction on my appointment. I attended my first meeting in January 2003. The only information I had prior to that meeting was the Trust's Handbook and the knowledge that I had already acquired through my husband's dealings with the Trust. I was also sent the Minutes from the previous meeting and the grant applications to read through prior to the meeting.

5) 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 trustee of the MFT.

6. The Board meetings were four times a year and the Working Party groups were scheduled to coincide with them, so I only had to travel to London once for both meetings.

7. The information for the next meeting would arrive in the post prior to the Board meeting. I would spend probably six to seven hours reading the Minutes and grant applications and making notes in preparation for the meeting. I would then travel up to London on the early train (about 7.00 am), attend the meeting, then catch the train home (at around 4.00 pm) the same day.

6) Please describe your understanding as to how, as a charity, the MFT was regulated.

8. I had very little knowledge as to how the MFT was regulated. I assumed that the Charities Commission and the Department of Health (DOH) would oversee the work to ensure it was carried out correctly. At Board meetings we would have a DOH official in attendance.

Section 2: Establishment of the Trusts and Schemes

7) The Inquiry understands from the above documents that you were a Trustee at the time when the MFT discussed the establishment of the Skipton Fund. Please describe your involvement with and/or recollection of the circumstances in which SF was established.

9. I am aware that there was a meeting to set up the Skipton Fund, but I did not attend that meeting, and was not present at the Board meeting in September 2003 when it was initially discussed.

10. My understanding at the time was that, as the MFT was already up and running, and had experience of the payment set up etc, that it would be cost effective to use MFT staff and offices to start up initially.

8) What did you understand the aims and objectives of the SF to be? What principles or philosophy underpinned its establishment?

11. My understanding was that the principles that underpinned the MFT, (referenced on the first page of the MFT handbook) were the same principles for the newly formed Skipton Fund. That is, that it was set up to administer financial assistance to beneficiaries.

9) What involvement (to your knowledge) did the Department of Health or any other Government department have in the setting up of the SF?

12. I was not involved with meetings that set up the Skipton Fund with the DOH and therefore am unable to comment.

Section 3: The AHOs

Appointments of Trustees

10) Please provide a description of the appointment process for the MFT and the exact composition of the Board during your tenure as Trustee.

11) What was the process for electing/re-electing trustees at the MFT? In particular, what involvement did (a) the Department of Health (or any other Government department) and (b) any other organisation or person have in this process?

12) How, if at all, were positions advertised?

13) 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?

14) How long did each trustee serve on the Board? Could a trustee be re-elected? If so, how many times?

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

Answers to questions 10-15

13. I was a user Trustee, which meant that I, or my partner, was a beneficiary of the Trust.

14. The user Trustee positions, of which there were two, were appointed by the

Haemophilia Society.

15. The Haemophilia Society appointed six Trustees and the DOH appointed four.
16. I saw an advert for the position in the Haemophilia Society Newsletter.
17. I was relatively new to the haemophilia community as I had only been with my partner (later my husband) for about two years. He had strong connections to the Birchgrove Organisation and the Partnership Group and I felt that as I was a Civil Servant with some legal knowledge, that this would be a way to contribute to the community.
18. As a newcomer, I felt it would be beneficial to be a user Trustee as I would see things with 'fresh eyes'. Also, I had recently started a law degree and felt that a charitable trustee position would help me progress within the legal job market.
19. After seeing the advertisement for the position, I spoke with Anne Hithersay on the phone, then with Roz Parkinson (MFT Office Manager) and Claudette Allen (MFT Social Worker) at a Haemophila event. After this, I then applied in writing.
20. I was then asked to attend an interview. I believe three people were invited for interview, and two people were chosen.
21. The tenure for a user Trustee was two years. I think that the user Trustees were only for that period, but other Trustees could stand for re-election. (although I am not certain about this).
22. Trustees were able to claim travel expenses. For example, the Trust reimbursed me for my train ticket and supplied lunch in the form of sandwiches and coffee at the office.
23. Some Trustees needed to stay overnight, and their hotels would be paid for by the Trust, but I didn't need to stay, as trains to South Wales were frequent and easy to catch either side of my meeting.

Structure of the AHOs

- 16) 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 MFT? Was information shared across the AHOs? If so, were registrants aware of this?

17) Please set out your recollection of the relationship between the different AHOs.

18) 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?

19) The minutes of a meeting dated 19 April 2004 record a discussion about the proposal for the SF to be appointed as Corporate Trustee of the MFT [MACF0000019_202]. What input did the DOH have as to the corporate structure of the SF and the relationship between the AHOs? What was your view of the proposed structure?

24. I am unable to answer questions (16-19) as the Skipton fund was not up and running until after I had left the Board.

20) To what extent was the MFT independent from Government? How much oversight did the Department of Health (or any other Government department) have over the MFT?

25. The DOH appointed four Trustees to the MFT Board. A representative, usually Zubedia Seedat, was present at the Board meetings. I had no other dealings with the DOH, so cannot comment.

21) Did you, or others within the MFT, raise any concerns and issues with the Department of Health about the funding, structure, organisation or running of the AHO, or about the involvement of the Department of Health, 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?

26. The DOH met with Peter Stevens, Anne Hithersay and the Treasurer and

funding was discussed, but other than hearing the report in the Board meetings, I was not involved.

22) What if any contact did the MFT have with the Department of Work and Pensions('DWP')/its predecessors in relation to welfare benefits?

27. I did not have any involvement in any dealings with DWP. The Trust had a Benefits Adviser who gave reports to the Board, but I do not think she was in contact with them directly.

28. The Trust had been set up a long time before I became a Trustee and I assume the questions had been addressed early on.

23) Please describe the working relationship between the MFT and the Department of Health. Were you aware of any difficulties? If so, what were they, how did they impact on the running of the Macfarlane Trust and how, if at all, were they resolved?

29. I did not have any involvement in any dealings with DWP.

Section 4: Funding/finances of the AHOs

24) 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?

30. I have no knowledge concerning the process.

25) 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 MFT?

31. I have no knowledge of the process.

26) 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?

32. I believe they had information at first from the Department of Health, but this was already in place by the time I sat on the Board. They obtained more in-depth information for beneficiaries when they sent out a census that asked for information concerning financial and family circumstances. They also held partnership group sessions which included beneficiaries who gave their views.

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

33. As I remember, we had £3 million per year.

28) Do you consider that the funding provided to the MFT by the Government was adequate? Please explain your reasoning. Was the MFT underfunded in your view? If so, what was the impact on the MFT of that underfunding by the Government?

34. At the time, £3 million a year seemed sufficient to pay the regular payments, grants and running costs as there was a reserve of money kept in the event that funding was not secured for the next three years. I assumed we had enough for each year (I believe that funding was agreed for a three year period).

29) 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.

35. I believe that the Trust could petition for extra cash, but I was not part of that process. I would have assumed that this was dealt with by the Treasurer and Chairman who dealt directly with the DOH.

30) Did annual or regular reviews take place during your tenure as Trustee? 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?

36. A review took place when I was a Trustee, which was run by an independent outside company. Please see Document 7 listed in the Rule 9 letter (MACF0000172_00) for details of the long term review.

- 31) Did the MFT have ad hoc meetings with the Department of Health during your tenure at the MFT? If so:
- a. How were these meetings arranged? Could the MFT call for such meetings?
 - b. Who set the agenda for these meetings?
 - 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?

37. I did not attend any meetings as stated above but I believe the Treasurer, Chairman and Chief Executive met with the DOH on several occasions during my tenure.

- 32) Did the MFT 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 MFT?

38. Not to my knowledge.

Financial management/governance

33) 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?

39. A financial budget was put in place – as seen in the Minute. Forecasts were discussed each quarter at the Board meetings. Regular payments were set, so could easily be forecasted. However, I am unsure how grants were forecasted. Whether it was based on previous years payments, I do not know for certain.

34) What was the impact on the MFT of spikes in applications and the amounts of funding being applied for?

40. By the time I came on board in 2003, the Trust had been up and running for several years and there were not huge amounts of new applicants approaching the Trust. I recall that if there was straight forward case, then the office dealt with it themselves, but if it was a more complex case, it would be brought before the Board for consideration and for a decision to be made. In my tenure there were only two cases that I recall being discussed at a Board meeting, and it was agreed that both would be taken on as beneficiaries.

35) 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?

41. The majority of the Board were not involved in the level of the reserve fund. I believe this was discussed on at least one occasion when a Trustee felt we should spend the reserves, and in the event of an emergency the DOH would have to give us additional money. I agreed that holding money back in the event of funding being withdrawn seemed to be over cautious.

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

42. Not as far as I am aware, but I had no part in those negotiations.

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

43. I have no knowledge of this.

38) 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?

44. I have no knowledge of this.

Section 5: The role of the user Trustee

39) Please describe your experience as a user Trustee and how you were treated by other Trustees serving on the Board during your tenure. Did you encounter any difficulties serving as a user Trustee?

45. I was treated well by the other Trustees. I was very young and still quite naive. Although I was a Civil Servant and accustomed to the formality of the Board, I was still quite nervous and was taken under the wing of both Pat Spellman and Elizabeth Boyd - both older respected Trustees. They explained procedures during meetings when I was unsure and gave me the benefit of their experience. I always felt that I was taken seriously and listened too when making a point, by both the Chairman and the other Trustees.

40) Were your views about matters relating to the Trust, including payment types and awards of grants, adequately taken into account by other Trustees when attending Board meetings? Please explain your answer.

46. I believe so. I can recall one meeting regarding a grant for financial assistance for holiday/respite. Another Trustee felt grants should only be given for stays at a care home, for example, for the registrant only. I felt that families and partners also needed respite and that a holiday for the whole family would be just as beneficial for the beneficiary as a respite stay in a care facility. My views were taken into consideration and listened to, and it was agreed that in future holiday/respite grants could be used for family holidays as well as nursing care.

41) Were there any decisions you were unable to participate in due to a conflict of interest? If so, please set out what those were, and how the situation was dealt with by your fellow trustees.

47. I did not have any conflicts of interest as far as I can recall, but if, for example, my partner had requested a financial grant, I would have left the room whilst it was being discussed and voted on.

42) Do you consider you were able to adequately represent the interests of beneficiaries as user Trustee? Why or why not?

48. Yes and no. I believe my comments and actions at Board meetings were always to the benefit of the beneficiaries. However, when I first started as a Trustee, I opened up a new email account with the specific intention of inviting beneficiaries to email me with their concerns, which I would take to the Board. When I discussed this with Anne Hithersay and Peter Stevens, I was told that this was not my role as a user Trustee, and that they had the Partnership Group in place for such grievances. I was informed that it was my own personal experiences and judgement that was needed on the Board. I did, however, always make myself available at MFT events in case beneficiaries did want to talk, but this was not done in any official capacity.

Section 6: Identifying beneficiaries for the Macfarlane Trust

43) Whose responsibility was it to identify potential beneficiaries for the MFT and how were potential beneficiaries of the MFT identified?

49. This was done before I became a Trustee, so I have no knowledge of this. The two beneficiaries who came forward while I was a Trustee were discussed by the Board. Both were referred through the Haemophilia Centre social workers at their relevant hospitals.

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

50. This was done before I became a Trustee, so I have no knowledge of this.

45) 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?

51. I do not think any more could have been done, other than what had already been done. However, I have no in-depth knowledge of this, as the Trust and its beneficiaries had been in place a long time prior to my being a Trustee.

Section 7: Eligibility for the Macfarlane Trust

46) What were the eligibility requirements (i.e. what an applicant had to show in order to be registered) and who set them?

52. I believe, an applicant had to prove they had haemophilia, had received blood products in the past and had a positive HIV diagnosis which their Haemophilia Centre Director could confirm. I am not aware who set the eligibility requirements.

47) Were eligibility requirements 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?**

53. This was all decided prior to me becoming a Trustee so I have no knowledge of these to answer questions a & b.

48) What procedure was followed by the MFT when registering an individual?

In particular, please address the following matters:

- 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?**
- c. Was a medical opinion required? If so, from whom and what issues was it expected to address?**
- d. 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?**
- e. What other documentary evidence was required?**
- f. 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?

- g. 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?**

54. I believe the Haemophilia Centre that the individual attended would supply the necessary information and it seemed like a pretty straight forward application process. The Board only saw a few that needed to be discussed, as the office staff normally approved them. The applications I saw were agreed, and the payments were set up relatively quickly, (including historical payments). As I recall, it seemed a very easy and straightforward process. Claudette Allen and the office staff were available to help fill in grant application forms, and I believe they were relatively easy to complete. I know from Cardiff's Haemophilia Centre, the Social Worker there would complete them and send in a covering letter to support any grants.

- 49) 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?**

55. I do not think that the system was reviewed, as it appeared to work well as it was.

- 50) Who determined whether a person met the eligibility requirements to become a beneficiary for the MFT?**

56. The office staff determined whether a person met the eligibility requirements and ultimately, the Board, if the staff felt they could not make a decision for some reason.

- 51) 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?**

57. I was not aware of any concerns or dissatisfaction.

Section 8: Decisions on substantive applications within the Macfarlane Trust

52) 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.**

58. Grants were made for different expenses such as funerals, education, boilers, moving costs, as set out in the handbook. All were assessed by office staff. If they were below a certain amount, it went straight through and only brought to the trustees' attention if the grant asked for was over a certain amount of money.

The process

53) Please explain who made decisions on applications for the MFT and how this changed over the time [font]you were involved. 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?**

59. As I have stated previously at paragraph 50, the office staff determined whether a person met the eligibility requirements and ultimately, the Board, if the staff felt they could not make a decision for some reason.

54) 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.

60. The written policies were already in place when I came on Board as a user Trustee and were contained within the MFT Handbook. I believe all registrants had a copy of the handbook. I have no knowledge as to whether the views of the beneficiary community were taken into account when setting the policies.

55) 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?**

61. Usually, an application for a grant would be dealt with by the office but if it exceeded a certain amount e.g. approximately £1,000, the Board would make a decision on that application. If for example, a new boiler was needed, then quotes for the cost of a new one would be required by two different companies (to compare the cost). Usually a social worker's report would be included to give more background. I was not aware of any individual unable to supply documentation or receive support from a social worker.

56) Were reasons for refusing an application provided to an unsuccessful applicant?

62. Yes, I believe that reasons were given by the office staff when denying a grant from an individual.

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

63. The decision on urgent applications would be made in the office by Anne

Hithersay with, I believe, Peter Steven's input.

58) What practical support or assistance was given to applicants to help them in making applications.

64. I understand that hospital social workers, or Claudette Allan, the Trust's Social Worker, would help with potential grant applications. I would also think that Roz Parkinson the Office Manager was also very helpful.

59) In a MFT meeting dated 19 April 2014, the Board accepted a report from the Grants Working Party that a regular payment system was needed that "reflected individual need rather than any regressive formulaic approach" [MACF0000019_202]. Why was reform required? What changes were identified? Were these implemented? If not, why? When answering this question, you may also wish to consider the attached report [DHSC0003034_002].

65. I have no actual recollection of the Working Party Group or what was discussed. My understanding is that after I left, the Trust changed to a means tested system (after the census was undertaken), and this meant that different family set ups had different amounts depending on whether partners were working or whether they had children etc. The document also refers to single grants which did not at the time take into account savings held etc. Of course, with the introduction of Skipton on the horizon, it would mean that a lot of MFT beneficiaries would have a lump sum in their savings, so if this was taken into consideration then the application for grants would likely be reduced.

60) 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 MFT?

66. The success of each application was considered on its merits. No identification was given to the Board when considering a grant.

61) 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?

67. No

62) 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?

68. No

63) Please provide your view on the consistency and fairness of decision making by the Trust when assessing applications.

69. I think the Board was fair in its decision making, as no names or identifying comments were left in the application. I think sometimes, I felt the Board could be a little harsh in their comments, but I think that was far more with me being young and naïve, rather than then the Board being unfair.

70. For example, a beneficiary had lost their peripheral sight due to a bleed on the brain and a request for a grant was received to purchase a larger TV and computer monitor. Whilst the grant was for HIV related problems, not just haemophilia related, I was sympathetic to their need for some much needed relief by watching TV more easily. Some of the Board were reluctant, due to the fact that the blindness [font] may have only been temporary and therefore after a while, the need for the larger TV would not be needed. I felt that we should consider the case as it was presented and not look to the future. I believe in this case we did grant the finance with the help of Claudette Allen's input.

Loans made by the Macfarlane Trust

Please consider the following documents when answering the questions below:

- i. Minutes of the MT Board meeting held 28 July 2003 [MACF0000009_179]**
- ii. Minutes of Macfarlane Trust Trustees meeting held 12 May 2003 [MACF0000009_081]**

64) 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 Macfarlane Trust's charitable purpose.

71. Loans were already offered prior to me becoming a Trustee, so I have no knowledge of the process.

65) Please describe the different types of loans and advances provided by the Macfarlane Trust to beneficiaries.

72. Interest free loans and low interest loans were offered in place of grants and money, then deducted from monthly payments. Loans were also given against equity in an individual's house, but as I recall, I was only involved in one such case over the two years. However, I know there were more in existence, but I understand that they were very few and far between.

66) In a meeting dated 28 July 2003 [MACF0000009_179] it was noted that Trustees felt strongly that financial help given to relieve debt should only be given as part of a structured plan and monitored closely. Who monitored these plans? 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?

73. The plans were monitored by the office and a Social Worker. I believe that the Financial Advisor was also required to be involved.

67) Please describe any role you had in approving loans and/or advances made by the Macfarlane Trust to beneficiaries. You may find it helpful to refer to [MACF0000044_007] when answering this question.

74. I believe this was the only loan of this type that I was involved in. It was discussed in the meeting and explained to GRO-A (the other user Trustee) how it worked, and trustees had to agree to the loan. This had been done on several prior occasions, so I agreed to this being done.

68) Please describe the criteria used to select recipients for the different types of loans made by the Macfarlane Trust to beneficiaries and confirm who drafted those criteria.

75. Smaller loans/grants etc were not seen by the Trustees. The larger grant applications were referred to the Board. If it was felt that the grant did not meet the criteria, a loan could be offered in its place. This was done, as far as I am aware, on an individual basis and on the merits of the application. Obviously, some registrants had knowledge of the loans from speaking to other beneficiaries and asked for them. There may have been written criteria in the office, but as far as I am aware, we agreed/offered loans on a purely individual basis.

69) Please confirm whether the Macfarlane Trust 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?

76. I believe the loans had been looked at by the Trust's solicitors and Suzy Daniels, the Financial Adviser. I was given this information as hearsay by Peter Collins and Anne Hithersay at the Board meetings.

Non-financial Support

70) 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?

77. The Trust employed a Social Worker and a Benefits Adviser and offered the services of Suzy Daniels as a Financial Adviser. Grants were also available for counselling. Referrals for counselling were made to the Terrence Higgins Trust. This was arranged by the Social Worker, Claudette Allen, She worked closely with the Haemophilia Society and their Social Worker, Barbara (Babs) Evans.

71) The Inquiry understands that the MFT had social workers and debt and benefits advisors available. Was there much take up for their services during your tenure? Was this support welcomed by the beneficiaries in so far as you were aware? If not, why not?

78. I believe there was, I know my husband and I used the services of all of these. I recall Suzy Daniels' help was particularly sought after. At the time, banks and building societies were not giving mortgages to registrants as they did not include the monthly MFT payment as a regular income. Suzy had contacts at a building society who agreed to offer mortgages, so she was in great demand. Carol Clisby, the Benefits Adviser, also helped in offering advice and support when contacting DWP.

Section 9: Complaints and appeals

72) 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 any 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 the review/appeal? Was the original decision-maker permitted to be present or make the decision?**
- e. Were written reasons for the decision provided?**
- f. Where there any time limits or fees for the bringing of a review or appeal?**

79. Appeals for grants were done by letter. As the grants were confidential, registrants were not offered the chance to speak in person. The appeal would be heard by the Board. Claudette Allan would usually speak for the applicant. As far as I am aware, no time limits or fees were involved. There was a special Board who could hear appeals, but I was not involved.

73) How common was it for decisions to be appealed and how frequently did appeals succeed?

80. I am not sure. I know if a grant was denied, then an appeal could be made, but I'm not sure how many did this. If further evidence was given at the grant appeal, then it might change the decision, but I cannot say with certainty how often this happened.

74) Was there a complaints process? If so, how did it operate?

81. I don't have any information about this.

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

82. There were a few complaints when I was on the Board, one or two about the staff in the office. But they were usually dealt with by the office manager/CEO. The main complaint was against one member of staff who could be quite rude and unhelpful on the telephone. I know from my own experience when calling, that his manner was very abrupt. He was a very good worker and extremely good as his role but had very little in the way of telephone technique and I was aware of a few people complaining about his manner. I believe that Anne Hithersay and Roz Parkinson had both spoken with him regarding the complaints, but I think that was as far as it went. However, I can recall a meeting when it was brought to our attention that a beneficiary was extremely rude to him and Peter Stevens spoke to the individual directly about being rude to staff at the office.

76) What information was provided to beneficiaries about the appeal and complaints procedure?

83. I don't have any information about this.

Section 10: Engagement with the beneficiary community

77) What steps did the MFT take to engage with and understand their beneficiary community?

84. A census was undertaken to understand the circumstances of the registrants and the Partnership Group met regularly. An internet chat room was set up for MFT registrants, but trustees were not allowed to participate as it was felt that registrants needed to feel secure in speaking freely on the site.

78) The Inquiry understands that you were part of the 'Working Group' set up to engage the Partnership Group in consideration of the future of the single

grant and regular payment system (see the report on the Trustees' Away Day held 1 December 2003 [DHSC0003034_002]). How successful was the Working Group in achieving this? Please give details.

85. I have re-read the Minutes attached and I am sorry, but I have no recollection at all of whether it was successful.

79) Regarding the Partnership Group, please answer the following questions:

- a. What was the purpose of the group?**
- b. How often did meetings take place?**
- c. Who set the agenda?**
- d. Who attended the meetings and how were the beneficiaries selected for these meetings?**
- e. What impact, if any, did these have on the way the MFT operated?**
- f. Were there any problems encountered in the running of the group and how were they handled?**
- g. Were there any other groups or meetings involving the beneficiary community during your tenure? If so, please provide details.**

86. I have very little knowledge of the Partnership Group. The trustees were discouraged in getting involved by both the group itself and the Trust. A few particularly militant members were very vocal about trustees spying on the group, so I kept contact to a minimum. I felt that for some of the trustees, the Partnership Group was seen as a waste of time. Although I believe this was due to one or two militant members (as referred to in Peter Stevens evidence) and not the whole group. There were other groups I believe, one for gay registrants, a Scottish group, a group for the Eileen Trust registrants and also a very successful bereavement group.

80) 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?

87. I think, on the whole, the senior Board members had a good relationship with the registrants, and it was only a small minority of registrants who wanted to cause friction. Myself, and the other user Trustee, had a different relationship with the beneficiaries, as we could be seen as "one of them" rather than the

Board.

Section 11: Relationships with other organisations

81) What involvement or interactions did the MFT have with the Haemophilia Society?

88. There was a good relationship as far as I was aware between the two. How involved they were day to day though, I have no idea.

82) 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 MFT and how if at all, were they resolved?

89. There was a good relationship as far as I was aware between the two, but I have no idea how involved they were day to day.

83) 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.

90. I don't think so. I think GRO-A might have gone on after to be a Trustee of the Haemophilia Society, but I'm not sure. We took the role of Trustee seriously, and I think when sitting on the Board we were as professional as possible, so any differences between the two organisations were not a problem.

84) What involvement or interactions did the MFT have with the UK Haemophilia Centre Directors Organisation? Please describe the working relationship between the MFT 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 MFT and how if at all, were they resolved?

91. I am not able to answer this question. I have no information about this.

Section 12: Other

85) Please provide details of any consultation or reform process you were involved in, in respect of the MFT.

92. I was a member of the working party to improve grants and payments for the Trust, which I hope did have some effect after I left.

86) 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?

93. I believe that it was run as well as it could be. Office staff were extremely helpful and efficient. However, after Anne Hithersay left, and Martin Harvey took over the role as Chief Executive, the office became more streamlined. This is not intended to say Anne Hithersay did not run it well, but that a different management style gave the impression of improvement

87) To the extent that you have not already done so in a previous witness statement to the Inquiry, please describe your personal experience with any of the Alliance House Organisations as a beneficiary.

94. I did not have any personal experience as my husband was the beneficiary, so all correspondence was through him. As a Trustee, however, going into the office prior to meetings, I was always warmly welcomed (same on the telephone) by the staff, who were all very helpful, especially Claudette Allan and Roz Parkinson who became friends as well as colleagues.

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

I do not have any other information or documents relevant to the Terms of Reference.

Statement of Truth

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

Signed.

GRO-C

Dated. 24.11.21