Witness Name: Stuart Gregg
Statement No: WITN1252013
Dated: April 2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF STUART GREGG

I, Stuart Gregg, will say as follows:- .

Section 1- Introduction

1. My name is Stuart Gregg, DOB GRO-C 1975 and I live at GRO-C GRO-C Worcestershire, GRO-C My role with the Macfarlane Trust ("MFT") was in the capacity of a User Trustee.

2. Some of these questions won't be particularly relevant as I was a User Trustee and my qualification for the position was primarily through being a registrant. I wasn't in employment from the age of 18 (1993) onwards, due to ill health. I also left a university course during this time due to ill health. During the period 1998 to 2006 I achieved an undergraduate degree, followed by an MA in Social Research, then studied and worked at the University of Birmingham in the Social Sciences Department, whilst working towards my (never submitted) PhD. I have been employed on a "zero hour's contract" with G4S, near to where I live, between 2007 to 2020 to earn enough money to be able to get by. I have not worked since March 2020 due to ill health from the Covid pandemic.

3. I was appointed as a User Trustee of the MFT in about September 2003 and served until mid 2007. I responded to a vacant position. I set out in paragraph 8 below how i came to be appointed. I served on various committees such as

the NSSC and the MFT Partnership Group. The Partnership Group ("PG") was re-established circa 2004, following dialogue I had with registrants, I was initially the Chair. The PG began to lose emphasis and perceived influence towards the end of my tenure, later it stopped altogether and was not seemingly encouraged by later CEO's of the MFT when it seemed there was much less collaboration between the registrants and the Trustees. At this point MFT seemed to become more of a vehicle for delivery of funds rather than necessary additional support.

4. My role as a User trustee was to attend Board meetings and sub-committees of the MFT, such as the NSSC or PG. During my time as an MFT User Trustee it was always difficult to maintain a balance between my role with the MFT and my expectations as a registrant. To undertake my roles and responsibilities correctly and fully, in the terms of the role of a User Trustee, I often had to attempt to consciously separate my individual experience as a registrant from my duty and responsibilities as a Trustee. Of course, these two things became inextricably linked and it was near impossible to undertake the role at times but I committed to the role in the best way I could. It was about attempting to build relationships and trust between people and organisations – to create a tangible link between the MFT and the registrant community. The role required an element of diplomacy, it would not have helped to demand certain things, at the same time it was important that the feelings of the MFT community were strongly highlighted and expressed in any given situation, moreover that people felt their voices were being heard.

5. I do not recollect any formal induction or training. However, the Chief executive, Ann Hithersay (later Martin Harvey) and staff were always willing to help with any queries I had. Due to my age at the time (28), and the different experiences I'd had compared to men who were infected as adults, I had to learn a lot about my community. Although I had been on other committees before joining the MFT they had never been on such a large and important scale than as with the MFT. It is a role that I took very seriously.

6. Prior to my role as a User Trustee I had done voluntary work at both an Advocacy centre and an HIV organisation close to where I live, I had also been

on the committee of that HIV organisation. I'd had some interactions with the Birchgrove Group before becoming a User Trustee at MFT. Increasing my knowledge base and user involvement within our community became very important to me. I remain in touch with some people from my community who are still alive, including Tainted Blood which was initially a web archive project idea that was borne out of the Partnership Group.

7. I have been involved in some research projects and was involved in the 1991 ex-gratia settlement (as a child) although I had little knowledge of what was going on. I was also involved in the American litigation. Apart from the above I have not provided evidence or been involved in any other inquiries, investigations or Criminal or Civil litigation.

Section 2: Your appointment as a Trustee

8. I think the vacant position was advertised in an MFT newsletter, and I made an application. I don't think they had many applicants. I travelled to London for an interview with the then Chief Executive, Ann Hithersay. I was formally offered the role soon after. As far as I can recall, neither the Haemophilia Society nor the Department of Health ("DOH") had much involvement in the process.

9. My role as a User Trustee did not necessarily differ to that of other Trustees, however it was inevitable that, as a registrant, my position held a slightly different feel in terms of its proximity and shared experience to the registrant community. I had no obligation to report to the registrant community. However, I felt that the notion of "user involvement" was pivotal to be able to meet the needs of the registrant community, therefore it was important for me to try and establish closer ties between the registrant community and the MFT. This was done mainly through my involvement with the Birchgrove Group and re-establishment of the PG. I was also aware of my legal obligations as a trustee.

10. I felt I was treated equally as a User Trustee and that my voice as a registrant was taken seriously and was much more than mere "tokenism".

Section 3: Establishment of the Skipton Fund

11. I can recall when the Skipton Fund ("SF") was being established and as a User Trustee I would have been supplied with information on how this was progressing and the reasons for the establishment of the SF, in respect to the framework and parameters in which it was incepted. I found the legal and structural frameworks behind these decisions to be rather complicated and I don't recall why the particular mechanism (piggybacking onto existing structures) was chosen or what other structural options might have been available. I had very little involvement with the SF.

12. My understanding of the SF was that it was being established to administer funds to those people infected with Hepatitis C through blood products. I was not aware of any particular principle or philosophy underpinning the scheme, it seemed simply a mechanism that was developed solely to distribute Government monies to those identified beneficiaries.

13.

a) I was not involved in any consultation with the DOH; these would have been led by the Chairman, Peter Stevens. I can count on one hand the number of times I saw representation of the DOH at any meetings to which they were invited to. I felt that the Government considered the inadequate funding to be their only responsibility within the MFT and its various schemes. The hard work and effort was left to just a very few good people who had best intentions but weren't given the necessary tools or funding by the Government.

b) See above.

c) As in paragraph 11 above, I was never certain why the Government decided to distribute the monies via the SF rather than directly. I can only assume that it was felt that as the MFT structure was already in place then the SF could be incorporated into this to facilitate the distribution of the monies. I can't recall what were considered to be the risks of this structure and I should imagine that one of the benefits was that it was much cheaper to structure in this way, using the knowledge already in place at Caxton House.

d) No, I don't remember this ever being discussed.

e) This has been a constant discussion for MFT registrants, for SF beneficiaries and, to a lesser extent, those involved in administering the schemes. Due to the way these schemes were rolled out from the very start, and how poorly they were structured and funded (particularly the MFT), it created further fragmentation and anger between those infected/affected by contaminated blood products. If this issue had been correctly addressed at the start it would've prevented much unhappiness, poverty and grief.

f) I refer to the above paragraph.

(i) Many people in these communities have been let down and poorly supported, the differences between the schemes only served to highlight this. These feelings were known to the board of the MFT, however without further Government support/financing there was often very little that could be done to widen the support that was being given. The MFT was unable to support its registrants properly, despite there being clear evidence of such high mortality rates and ill health. There were so many people who needed support in many ways, particularly financial assistance but also psychological support, access to social workers and benefits advisors.

Section 4: the structure of the MFT

14. The different AHO's were separate, yet there was a certain linkage between them in that they were organised and run via Alliance House. Personally, I was only ever involved in the MFT.

15. During my tenure as a trustee (approximately 2003-2007) I never found there to be any issues or difficulties between the Trustees and the Senior Management at the MFT. Ann Hithersay always seemed to be very well liked, however she retired shortly after I started. Martin Harvey always seemed to have a good and strong relationship with the Trustees. I'd say during this period the relationship between Trustees and Management was generally strong, rigorous and constructive.

Section 5: Identifying beneficiaries

16. Identifying new MFT beneficiaries was not a common occurrence and I can only recollect one or two situations when this occurred. I'm not sure who was specifically responsible but would imagine in the first instance it was dealt with by the Chief Executive.

17. Not applicable, please see my answer above.

18. I wasn't aware of the process that was involved or what input MFT staff had in helping and directing potential new MFT beneficiaries. This was a rare occurrence so I should imagine new beneficiaries approached the MFT directly. Obviously, this would have been very different to the process required when the SF began.

19. I believe the MFT did take steps to engage with and listen to the registrant community, although it must be noted that I am only speaking in reference to the period in which I was involved as an MFT trustee. Firstly, having "User trustee" positions gave an initial outreach to the registrant community. From that position we were able to further establish the PG, although I'm not aware how much liaison there had been through the PG prior to 2004. This Group was pivotal in creating understanding between the registrants, MFT staff,

management and Trustees, all of whom were encouraged to attend PG meetings. People could attend meetings or submit queries and the PG would discuss those. It gave an open forum and honest voice for the registrant community and helped create a tangible relationship with the MFT. For a short period of time "user involvement" was in place and working well within the MFT.

i) Whilst the PG may not have created instant resolution to some registrant's concerns, it went a long way in aiding understanding and trying to create a better MFT over time. Martin Harvey would always make himself available to speak with registrants and try to understand their perspectives on how to improve things for the registrant community.

ii) Some discussions from the PG, such as creating a web archive for our community, along with the knowledge that members of the Birchgrove group brought, would be catalysts in the creation of Tainted Blood. In addition to the Partnership group, the MFT in co-operation with registrants, were able to begin weekends away where registrants could meet up, have seminars, holistic therapies and realise they were part of a community. This created a more transparent and trusting relationship with MFT. It is through these types of groups and events, which the MFT helped deliver that I grew to understand my community, share its experiences and knowledge from people of all ages, whom I felt a shared experience and relationship with. I have built and remained strong friends with several people in this regard as our shared experience is something that few people understand.

iii) Bringing together all these people was a real positive. Unfortunately, this type of engagement and collaboration sadly fell by the wayside over time. I think much more could have been done by the MFT in recent years, I can only comment from my perspective as a registrant that in its latter years it felt more clinical and that any collaboration such as mentioned above was seemingly discouraged.

Section 6: Relationship with Government

20. I don't know exactly what involvement the DOH had with the MFT. The initial structure of the MFT would necessitate that it would always be under the guidance and rule of the Government, if they chose to take an interest. The MFT seemed able to operate relatively independently from the mechanisms of Government, however there was always an underlying notion that the MFT had to display that it was operating effectively to meet the requirements of the DOH. The MFT was always in a lose-lose situation because of the way the it was structured and funded in the first instance. It had to do its best so that the Government did not threaten to remove funding. However, the MFT could never meet the needs and requirements of the registrant community, in any sufficient manner, with the kind of funding and support that was given to the MFT.

    i) The registrant community often wanted the MFT to lobby the Government to achieve greater funding – however, it was not considered the role of the MFT to lobby, as the MFT was merely a conduit of the Government to dispense the funds allocated. The MFT could attempt to display through means such as the Long-Term Review that more funding was required but this always fell on deaf ears.

    ii) As a registrant, and a User trustee, I felt that the Government had almost zero interest in what the MFT were doing, so long as there were no major issues happening. In the time that I was a trustee I can only recall seeing a representative from the DOH attend a meeting on a few occasions. When they did it really felt that they had no idea what the MFT was about or what it was trying to achieve. The only concern seemed to be potentially reducing the amount of funding the MFT might get in the future. It is important to note that I was on the periphery of things, so my perspective may have been different to those more deeply involved.

a) I don't know what involvement the DOH had. A trustee on the board was an ex-employee of the DOH and they were always invited to attend meetings but very rarely did.

b) They just provided the funding. As far as I am aware there was very little, if any, input from the DOH when it came to MFT policy through the period I was in tenure

c) As above, the DOH had no input in this as far as I could tell.

d) As above

e) As above

21. The structure of the MFT was something that had existed for well over a decade by the time I joined. I always felt it was far from perfect, but we were dealing with a historical legacy and only vast reform might change that. As far as I know the structural issues were not raised to the DOH. The structure became more convoluted as Skipton was absorbed into the AHO. As far as I am aware the DOH never looked favourably upon any requests for increased funding. In fact, towards the end of my tenure I can remember there being real concern that the funding would be vastly reduced. From my position it always felt that the DOH only paid "lip service" to the MFT, they weren't really interested and let things continue as was. There was no interest in the community and they wanted to give the same level of funding to keep things ticking along. The issue of the reserve was raised at the partnership group as registrants were concerned that having such a large reserve meant an increase in funding would not be provided.

    i) The MFT on occasion made a case for increased funding, such as through the Long-Term Review. However, it was always felt that the DOH shouldn't be "poked" too much as they controlled the funding, so any representations had to be made but in an appropriate manner. Through the PG concern was expressed that funding was not being increased but I cannot recall specific details of any response.

22. The MFT did have a social worker in place for a period, but for the majority of the MFT's existence there was no social worker or benefits advisor. The staff at Alliance House had to deal with many cases where registrants had had their benefits stopped directly as a result of monies received from the MFT. Martin Harvey tried to get a benefits waiver put in place. During my tenure, the MFT did try to get all registrants some kind of immunity from their MFT monies being considered by the DWP, but it was a difficult task dealing with a different branch of Government. This was always an area that registrants voiced concern about and which caused them genuine worry, even financial hardship.

Personally, I was called in for an interview by my local authority in the mid 1990s, which turned out to be a fraud interview. It was only when I was forced to disclose my status and the MFT in the interview that things became less aggressive.

g) Yes, it was quite common that registrants would have their benefits stopped and get into financial difficulty. The MFT would intervene but, as mentioned above, it was never able to get a blanket policy to cover all MFT registrants from the DWP in those days. The DWP had no idea they should not take MFT grants into account. This was never properly resolved.

h) Yes, as far as I am aware, the MFT did take action to help and support registrants when they were made aware of this happening.

i) Yes, in my knowledge this was raised repeatedly with the DWP although it was not met with the support required from them.

23. The MFT would have a main point of contact at the DOH – I remember the name Richard Gutowski – who would report to the Minister at the time. It was very rare that the DOH would attend meetings, when they did it would normally be a junior representative sent. As mentioned above I always felt that they never really knew or understood what the MFT was doing or trying to achieve,

although I have no evidence to support this. I had no confidence that the DOH were interested in being involved in the MFT.

Section 7: Funding/finances of the AHOs

24. I was not involved in the financial structure of the MFT, although it was discussed during Full Board committee meetings when required, it always seemed rather convoluted. The main thing I recall regarding the financial side was the concern that funding to the MFT was never guaranteed in the mid to long term. This had a knock-on effect in how the MFT subsequently used and allocated its resources and funding.

25. As mentioned above, I had very little input in this side of things. The main hope was that funding would be maintained. Of course, the MFT should have been listened to more by the Government, especially after providing evidence such as the Long-Term Review and how registrants' needs were changing over time, with long term health care needs and home adaptations etc. As far as I could tell the Government took very little notice of any representations made by the MFT. I do not know the mechanisms which decided the funding but the MFT was always under resourced.

26. The MFT held standard information on their registrant community. My first impression was that data was generally quantitative and statistical rather than qualitative. However, circa 2003 a Long-Term Review of the registrant population was undertaken and commissioned to Hilary Barnard. This document was to form an overview of the future needs and requirements of the registrant population.

    i) There was regular contact with the registrant community via forums such as the Partnership Group and the MFT weekends. It was recognised that large parts of the registrant community needed more financial support which was unavailable through the parameters of the Government funding during those years. As far as I am aware this information was provided to Government officials, although I'm not aware who did that and why it was not acted upon.

ii) In the years after leaving my position of Trustee I felt that resources available to support the registrant community became scarcer and that the general feeling amongst the registrant community was that grants would not be given.

27. No, I don't believe the funding was adequate in any way. Quite the opposite. From personal experience I know I got into debt and this caused a lot of worry and concern. This was exacerbated by the cyclical nature of being unable to work for large periods due to ill-health. As a trustee I heard many stories of similar situations where the registrant community lived almost from hand-to-mouth, in abject poverty, with most opportunities to work or generate income, taken away by the health conditions those people were living with.

28. I was not aware of any additional monies being available to the MFT.

29. I wasn't aware of annual reviews that the DOH made of the MFT. As mentioned before there seemed to be very little involvement from the DOH.

30. The MFT was able to signpost people to alternative sources of funding or grant making bodies. This was always met unfavourably by registrants because it often meant that they might have to disclose their status to another organisation who would not be familiar with the situation. I cannot recall any other sources of income for the MFT, as it was strictly funded by the Government. I do recall once that some money was left in an individual's Will, to be used for the purpose of supporting other registrants. Although that would have been a small amount in relation to the general monies of the MFT.

Financial management/governance

31. As trustees we had view of the financial accounts. I cannot recall how the budget was allocated in respect to the amount forecast to meet registrant needs. These matters were dealt with by the MFT management and/or the trustee with finance responsibility. There was a significant contingency reserve

budget which was maintained by the MFT in case funding from the Government ceased.

32. I don't recall there being "spikes" in requests necessarily. There was a list of eligible items that could be applied for, alongside a timeframe before which an application for that particular grant could be made again. This meant that there was always a certain capacity built in to some extent.

   i) I had always felt, and stated regularly, that the whole grants system of the MFT felt unfair, flawed and inequitable in its very nature. Those who understood the system knew how to access grants and support, whilst there were registrants who either didn't know how to access the MFT or thought that someone else might need the money even though they were in dire need themselves. My thoughts were usually met with agreement on the Trustee board and within the registrant community. It was considered that there was no better operational system, considering the budget restrictions imposed by Government.

   ii) I don't believe the Grants system was robust and certainly didn't work for everyone. This was not through a lack of trying from the people running it but, again, caused by the lack of funding.

33. This is hard to ascertain. It certainly could be viewed that the Government might consider the MFT was financially comfortable as they were holding a reserve. Another argument would suggest that prudent financial planning by the MFT ensured the Government were confident in the financial management of the MFT and that should then mean funding would be renewed.

   i) A view strongly held by some registrants was that the reserve was money assigned to the MFT to support registrants in need and that it was just sat there doing nothing. I can understand having some reserve, particularly in instant access accounts I certainly didn't agree that the reserve needed to be as large as it was.

34. I'm not aware of what steps were taken to cut operational costs.

35. As I recall, during Trustee meetings, it was stated that staff salaries were in line with similar sized charities for each role. I also recall that when Martin Harvey was in post that it was stated that his salary was considerably less than other chief executives working in London. I cannot recall whether that was in reference to the charitable or private sector. Someone with better knowledge of these areas would be able to answer more appropriately.

Section 8: the work of MFT

Eligibility

36. I'm not sure what is meant by "eligibility requirements". I assume it means the eligibility for an individual to become a registrant of the MFT.
If that is the case, then I was not aware or consulted about the eligibility requirements. My understanding of the MFT was that from the very early days of the disaster that it was widely known which haemophiliacs were infected with HIV. There were only very few occasions later on where the MFT would take on a new registrant. When I was a trustee I don't recall any particular issues with applications.

37. There were no periodic reviews of the eligibility requirements, as I recall. I remember an application would normally be made by a doctor or a GP.

38. As mentioned above, this happened only on very few occasions. I am not aware who took on that role.

39. Not applicable – I was not the person responsible for these decisions.

40. As mentioned above, these applications were few and I don't recall any specific issues with the criteria or eligibility requirements. I should imagine that out of all the AHO structures then the MFT was possibly the easiest to navigate with these issues during this period.

Decision-making

41.

a) There were certain grants that could be authorised by staff, under specific guidelines. As I recall this would be done by Roz and Keisha during the period I was a trustee. Any applications for grants that were made outside of these guidelines would be passed to the MFT trustee board to consider. This was also the case when a registrant had received more than a certain amount within a stipulated period. The creation of the NSSC occurred during my tenure as trustee to facilitate the application process.

b) The NSSC was formed to consider grant applications received that were outside the parameters that the office could authorise and to avoid having to wait until full Board Meetings. I was part of the NSSC, alongside Elizabeth Boyd and Martin Harvey. I cannot recall the other trustees who were on the NSSC. I'm not aware of the specific criteria for those selected to be on the NSSC. The NSSC met every 3 months as I recall. The NSSC would consider each application on an individual basis, based upon the grant application guidelines, and thereafter make a decision.

c) As I recall, the full Board would only review grant applications which were appealed. The full Board would have agreed the parameters and process of the NSSC prior to its inception.

42.

a) There were a set of guidelines for grant applications. These were printed and sent to registrants on an annual basis, as far as I can recall. These were the same guidelines with which applications were considered during my time at the MFT.

b) I'm not sure whether any medical or expert advice was sought in the initial set up of the guidelines. These guidelines were in place when I arrived at the MFT, however I am sure they would have changed over the years of the existence of the MFT. I'm not sure how they would have been amended, or by whom, during this period.

c) I'm not sure what happened when the guidelines were originally set up. However, when I was a trustee I know that via the PG, or events such as SFTW, the MFT might reconsider certain areas of grant applications, if issues were raised to them. One example, during my tenure, might be respite care or access to holistic therapies.

d) All the available policies would be able to be seen in the booklet distributed to all registrants annually during this period and grants covered a wide range of needs and requirements.

43. It is difficult to recall, without reading the guidelines, what elements differed between different application items. Towards the latter years of the MFT it became so convoluted to make a grant application that I ceased trying. It often felt demeaning, like having to "beg" for any kind of financial assistance and the refusals became too frustrating and upsetting. Certain elements such as obtaining three quotes for an adaptation would be often difficult for a registrant to arrange at times, depending on their situation. When I was a trustee, quotes were often required before certain grants would be approved. Sometimes a Doctor's note might be required, depending on what the Grant was for. With the structure in place, it often became a question of who was willing to "jump through the hoops" to receive a grant if it required additional supporting evidence, letters or material. Some registrants, for many reasons, were unable or unwilling to do this.

a) I cannot recall this but the standard of proof would presumably be found within the grant guidelines document.

b) I cannot recall exactly, but I believe the requirements were reviewed. I was a trustee when Martin Harvey started his tenure and many things were re-visited at this time.

c) Yes, there were occasions when it would be brought to our attention that a registrant wasn't aware of their eligibility to make applications, or felt they weren't in need when they clearly were. In those situations, the MFT actively encouraged and supported registrants to make use of the grants application system.

44. Yes. As I recall, a letter would be sent to a registrant stating whether their application had been successful. If they had been unsuccessful then reasons would normally be given as to why.

45. Yes, there was a procedure in place for approving grants on an urgent basis. I can't recall the exact structure of how it worked.

46. There was little practical support given by the MFT trustees to the registrants to make applications. Some registrants had social workers in their Haemophilia Centre who could help with this process. Many registrants relied on the help and advice of staff at the MFT, such as Roz Riley, who was a very well-liked and respected member of staff at the MFT. Every registrant I ever met thought the world of Roz, she was a wonderful person who cared greatly for the registrants and always did her utmost to help. However, she carried this out within the parameters and guidelines of the MFT application process, which was a very difficult task to balance. It was hugely disappointing for registrants when Roz left the MFT.

47. –

a) Regular payments ("Reg Pay") were made on a monthly basis to registrants. As far as I am aware each registrant received the same monthly Reg Pay. Registrants with children received an additional payment per child. In the 1990s I seem to recall the reg pay amount being circa £250 per month, even just a few years ago this had only risen to circa £700 per month, which simply wasn't enough to support the most basic financial needs of this community.

b) By lump sum payments I presume it is meant the initial payments made to each registrant. These have caused much upset with registrants. Married men with children received a pitiful sum, which people felt forced into accepting because they were told nobody would receive anything if they all didn't agree to the payment. Given people were scared (for their health) and in desperate financial need it is hardly surprising that registrants felt backed into a corner. Those over 18 without children received approx one third less than those with children, finally those under 18 received approx two thirds less than the men with children. The whole system was conducted in a shambolic way. At no point was consideration or empathy given to the care and well-being of this community.

c) I cannot recall. For further information on what was available via the grants scheme the annual document gave a full overview.

48. Not necessarily, during my tenure each application was judged on its merits and in accordance with the application guidelines. The overall number of applications made by a registrant could mean that the current application be reviewed by the NSSC, rather than dealt with by the Office staff. There was no monetary figure that was used; however, it was possible to see when a registrant was receiving considerably more than other registrants in financial support. That doesn't mean that further grants would not be awarded, as there were nearly always individual circumstances, but it was one consideration of the Grant Applications process.

49. As mentioned in the above paragraph, the number of applications and the total amount of payments already made, might be considered in case they were considerably more than other registrants. I presume this was done to attempt to impose some form of fairness into a system which had been always inherently unfair due to being so poorly resourced by the Government. The MFT were attempting to make decisions to run the scheme as effectively and fairly as possible, in a utilitarian sense (the greatest good for the greatest number of registrants), when clearly the whole Structure and funding was inadequate in the first place. This was, again, the fault of the Government rather than the MFT.

As I recall, during my tenure, the monies received from other AHOs and Benefits were not taken into account in these considerations.

50. Grant applications were not means tested. During my tenure all registrants were able to make grant applications. However, during my tenure, scaled payments were implemented on Reg Pay (means tested), based on the income being received by the registrant.

51. During my tenure at the MFT I felt fairness and consistency was being used by both staff and trustees in decision making. I believe both staff and trustees did their best, within a structure that lacked resources to do the job effectively.

52. The report clearly states the extent to which the MFT is funded has a direct impact on how it operates and supports its registrants.

It is abundantly clear that widows of deceased registrants have often suffered terrible financial hardship. In my own household we have had the same conversation many times over the years regarding how difficult it would be for my wife to cope financially in the future, supporting our children, if I were to die.

i) Widows were often carers and gave up their jobs and careers to help look after their partners. Yet the MFT were unable to support them appropriately, due to a complete lack of concern and funding from the Government. Once the funeral costs had been paid, for which a grant was available, then the MFT often had little "financial responsibility" to support widows, when considering the Trust objectives. However, all Trustees knew that there was a great "moral responsibility" to try to do more for widows.

ii) There were moves to identify widows and explore how the MFT could help them, bearing in mind when I was a trustee some may have already been widowed for more than 15 years. Groups were set up to try and offer support but there was very little financial support available to make this an adequate provision. This is, once again, because the MFT was so poorly funded. When I was a trustee I heard very moving personal stories from some widows on how their lives had been affected by this tragedy and how they had not only suffered the loss of their partner but consequently suffered terrible financial hardship as a result.

53. This document demonstrates that the MFT trustees, at this time, were aware of the frailties of the MFT, inasmuch as funding was concerned. Throughout this document there is mention of helping registrants return to work, further user participation and increasing support to bereaved families.

    i) In relation to the quote "imbalance and even possible abuse" it again demonstrates that the MFT were not necessarily happy with the single grants scheme at the time. Abuse is perhaps a strong word to be used in this context. However, as previously mentioned, the MFT were aware that there was a clear imbalance in how some registrants were accessing financial support via the MFT and others weren't. As a registrant myself it was common knowledge that some people could "play the system" to their advantage, as they had the knowledge and skills to be able to do that. That should be perceived as a frailty of the system and an overall lack of funding, rather than perhaps "possible abuse". I often advocated for a simple increase in monthly Reg Pay for registrants, a situation which has now been put in place. Other registrants I have spoken to have said it gives them far more independence and security having the increased Reg Pay rather than a convoluted needs-based grants scheme.

    ii) I don't think it caused an overly suspicious or restrictive approach by the MFT during this period. It should be noted that I am discussing the years when I was a Trustee. I think in future years many registrants felt a much more restrictive and oppressive approach was taken by the MFT in offering support and grants.

54. Many registrants relied completely on the Reg Pay for day to day existence. However, from the perspective of the MFT having no structure stating that those payments should be legally made, then I suppose there is a juxtaposition in how both the MFT and registrants might view Reg Pay being a "right".

Personally, I think this is more of a comment from the report writer, trying to think "outside of the box" in reference to amending Reg Pay structure, rather than any indication that the MFT would stop Reg Pay.

i) Perhaps in a "legal" framework the report may be right. However, I certainly didn't take this view or approach in my thinking as a trustee and I always took the view that the MFT would not stop Reg Pay, at least whilst funding continued from Government.

55.

a) The MFT trustee board did create smaller "working groups" in various areas that would meet, brainstorm and then report back to the full trustee board. The working groups were often created in response to the recommendations established in the Long-Term Review, in an attempt to better meet registrants needs. I cannot recall how long this particular working group was operational. I am unable to say if it completed its objectives individually, although I would say more broadly that these working groups were a good way of separating certain issues and getting people to focus on particular areas.

b) I cannot now recall.

c) Yes, these Working Groups were usually a response to the Long Term Review, or any changes/generally thinking how things could be done better or differently, mainly after Martin Harvey took position.

56.

a) I cannot recall what was discussed in the meeting. I don't remember discussions about Reg Pay and grant allocations being influenced by monies registrants received from the Skipton Fund.

b) I cannot say for certain. I read this as meaning that there would have to be an evaluation of the number of grants that were being made if certain changes were made to the grants system. As the MFT had limited funds from the Government then any change to grants had to be considered as to whether it was affordable or would put a strain on the existing financial budget.

c) I cannot recall what an "allocations mechanism" was, or what it referred to.

57. This was my first meeting as a Trustee. I can't recall how the "monitoring Group" evolved or even whether it met again. The sentence highlights the lack of funding the MFT received and the fact that the Chief Executive felt that they had to be "creative" in trying to make funds last. This is a damning sentiment to how poorly funded things were. Reading the document, the meeting was attended by someone from the DOH, who demonstrated that they didn't have resources to do what was required in the Department.

The National Support Services Committee

58. I can't recall the actual aims and objectives of the NSSC. However, in reality it was a sub-group of the main Trustee Board that looked solely at applications and grants. As previously mentioned, it was done this way as it wasn't feasible for the whole Board to meet for this purpose. I was on the NSSC in my capacity as a user trustee, so I had personal experience of using the system. I think generally the NSSC worked OK but I don't think it was by any means perfect. It was difficult to think of other options of how it might have been structured, mainly due to the wider structure and lack of funding of the MFT.

59.

a) I was selected to join as I was a user trustee

b) As I recall, until the time I left the MFT as a trustee, it was the busiest group that I was on and met the most regularly. It took up a considerable amount of time.

c) I cannot now recall the exact number involved.

d) I don't remember exactly but I think it was Elizabeth Boyd, Dr Mark Winter, Martin Harvey, Roz Riley and myself.

e) We met every couple of months or so. I know the majority of my visits to London were for NSSC meetings as opposed to full Board meetings.

60. Those cases/applications which could not be dealt with by the MFT staff would be given to the NSSC for consideration.

61.

a) The members of the committee would be supplied with the booklet outlining what grants were available to the registrants. Before each meeting Roz would give a write up of each application and why it was being presented to the NSSC for consideration, including the reasons why it didn't meet the Office Guidelines.

b) I do not know what the rejection percentage was, but it was the role of the committee to look at each application individually and consider. There wasn't really a common theme as to what caused a rejection, there were many reasons which were often nuanced to each individual case.

c) I do not know the statistics, but I am confident that more applications were deemed eligible rather than ineligible.

d) Absolutely, Roz would take the decision of the NSSC and correspond directly with the registrant. She would outline the reasons for or against the application being accepted. I have received a rejection letter myself in the past, so I know Roz always dealt with it in a personal and empathetic way.

e) There weren't additional forms to complete for the registrants, as I recall. Once an application was required to be reviewed by the NSSC to review the original application and paperwork would be submitted by Roz unless the registrant wished to include anything additional.

62. There was medical and professional expertise on the NSSC panel. Whether it was sufficient for the task in hand was open to question. I generally felt it did manage to cover most areas, but there were times when it was insufficient. The NSSC could request further evidence if they felt they needed additional information. Certainly, the registrant community felt that the professional input could have been extended, improved and been more regular and robust. This, again, highlighted imperfections in the system such as how individual registrants perceived their respective need, which registrants had access to doctors and social workers who could make applications on their behalf, which registrants understood the grants system, how much financial resource the MFT was given and ensuring full professional competency on every level of Trustee meeting.

63. I can't recall exactly what was meant by this. When creating policy change there may have been unintended consequences that arose from such a change, which had not have been anticipated in advance. It should be up to the respective boards to review and reflect on those consequences and adjust accordingly when having a negative impact on the registrant community.
Respite breaks were an issue for the MFT to create a policy around. In the early days of the MFT a respite break may have been to a specific respite centre when a person was seriously ill and needed a break and where they could also get adequate care and attention.
Conversely, during my tenure, I can recall a request for a family trip to the Caribbean. The NSSC had to make decisions on what a respite break entailed and what was reasonable and responsible as a board to be permitting. It certainly was not an exact science. It again highlights how the grants system was not suitable and the registrants were being told what they could do or were allowed to be drip-fed, rather than having suitable Reg Pay each month.

64. Part of my role on the NSSC was to attend meetings such as these which might discuss policy and try to improve the current structure and policy to better meet the needs of the registrants. I think the general thrust of these minutes displays

that Mr Stevens was clearly trying to think of ways to better help the registrants, particularly those in the most need of financial help.

i) There will always be inequities in a system that attempts to disburse monies to such a wide-ranging group of people, a microcosm of society. No single method was the "best" or created fairness. If everyone was given one lump sum of MFT money, then is that fair for those who are unable to work or have severe limitations or needs, compared to those who can work or have other regular income? Conversely, having a grants scheme became unfair when access to that is dependent on many factors, some of which were out of the control of the registrants themselves.

ii) As I have previously mentioned, the support for registrants was never fit for purpose because the Government never dealt with the problem adequately in the late 1980s. That is what led to these inevitable inequities.

65.

a) I cannot recall why this decision was made. I would imagine it would be due to budgetary constraints that the MFT was under with the grant scheme.

b) In this document it does not state that £3,000 was a threshold which was absolute, it states that once £3,000 had been received in grants (or 4 grants) in that year, then anything beyond that would automatically be reviewed by the NSSC. That did not mean that further grants would not be received. During my tenure all decisions could be appealed by the registrants.

c) I cannot recall how this particular change in policy was communicated to registrants. However, the normal procedure for something like this would be either a letter to all registrants from the MFT or inclusion on a newsletter which went out to all registrants.

66. The policy changes to allow access for sperm washing for registrants would, presumably, have been developed by the members of the NSSC feeding into the main Trustee Board. I am unable to recall whether feedback was sought from the beneficiary community, however, it was not uncommon during this period of time, that matters such as these utilised feedback from forums such as the PG, or for the MFT to have sought the opinion of registrants. The MFT did support sperm washing, however even with these policy changes the support available was lacking.

67. I'm unable to answer this question in a meaningful way as I don't recall the workings of the NWC.

Non-financial support

68. Access to non-financial support was always something that we aimed to provide during the period that I was involved in the MFT. This was done through a number of channels, firstly the PG which might suggest/propose things that would benefit the registrant community, these might be explored and enhanced further at events such as "Something For The Weekend", which were excellent events that were run by and for registrants with the support of the MFT.

i) During these communications it would become clear that there were numerous issues' which registrants desperately needed help and support with, over and above the financial support that the MFT provided. This was mainly driven by the fact that many registrants were not involved in their local HIV community or local haemophilia community. They lacked a sense of community to a large extent and sharing information and historical experience was really important in learning to live with the conditions that registrants had.

ii) Examples of non-financial support and help might include benefits advice, and forums/seminars on living with HIV and long-term conditions, better diet, access to training, access to alternative/holistic therapies, respite breaks etc. It was also just feeling part of a community as some people had felt so isolated for so many years. It was meeting at events such as these, that people became involved with things like the Birchgrove group, which at that time was instrumental in organising the Woodland Memorial for those who had died, along with the installation of the memorial stone.

iii) These things may not have happened had the MFT been left to operate in isolation away from the registrant community. Having a dialogue with the community improved the PG and I felt that these activities empowered and enabled the registrant community. It was during these years that I remember MFT attempting to be more involved, at various levels, with the registrant community and being much more than simply a distribution channel of funds.

iv) Whilst things were still far from perfect, these notions of user involvement and participation, being acknowledged within the MFT, made it a much more approachable and interactive organisation. Sadly, moving later into the decade (the 00's) all these elements seemed to fall away until eventually the MFT seemed to become the polar opposite of what I would term participatory, being user led or with user involvement.

69. Yes. As stated above, these things were often guided by the registrant community, such as the weekend away events. These events and relevant support would have been in newsletters and how the MFT could potentially help registrants would have been discussed at event weekends.

70.

a) No, as far as I can recall this was not implemented during my tenure.
b) It was always felt that there needed to be additional social worker support that was tailored specifically to the registrant community, outside of the normal NHS signposted social workers, and who had good knowledge of the registrant community. In the earlier years of the MFT there had been social worker available via the MFT. Also, some Haemophilia CCCs had a social worker. The registrant community were largely keen to have a

dedicated social worker within the MFT. I'm not sure why this regional scheme did not become operational.

c) I'm not sure I understand this question; it may not be relevant if the regional scheme did not become operational. As it did not become operational then, no, there always needed to be more direct help from the MFT, even during this time, but most certainly in the latter years of its existence.

d) No.

Loans made by the MFT

71. I don't know how it came about. I can only assume those who were having difficulties approached MFT for support. Whilst it may not have been in line with the trust's approach they could:

- Refuse the request
- Give requested funds
- Provide a loan

As I can recall, requests for assistance could sometimes run into 6-digit figures, which would place the trust in a difficult position because if you give this support to one person then why can you not give to others? Sometimes loans were interest free, sometimes secured by a charge. I felt it was a difficult scenario for the MFT, they wanted to try to support registrants who needed help, but it was unfair to simply give the money if it also couldn't go to other people, due to the finite and limited resources of the MFT. The Trustee Board felt that giving loans/charges in these situations was a better option than refusing support altogether. People might think negatively of the trust in this regard but it was very difficult, trying to do what was best within these circumstances. Whilst registrants were safe in their home it was OK but often caused issues in the future when they came to move or sell their home.

72. There were secured loans, unsecured loans and advances. Secured loans became more regular towards the end of my tenure. I often felt this was a reflection of the financial hardship registrants were under. I myself was in debt that I had no way of escaping and had a secured loan (charge) against my property which was re-paid

to the MFT when I moved house. On rare occasions, for a specific purpose but not eligible under the grant system at the time, then the MFT might advance the money but reduce the amount the registrant were paid in Reg Pay over the forthcoming period of time.

73. I cannot recall the exact process, however the MFT registrants had access to the independent services of Susan Daniels.

74. I was only involved with those that came to the Trustee Board or the NSSC; I would have no other involvement in other cases.

75. Applications were made and were dealt with as they arose on an ad-hoc basis. The MFT did not select registrants for these types of loans/advancements, it was only offered when a registrant was in dire need and was approaching the MFT for support, such as I did on one occasion. Different options would be raised dependent on the amount of money requested and for what purpose that was required. It was not a "one size fits all" situation.

76. I'm not aware if legal advice was sought. I can recall that the Chairman or Chief Executive did speak with people who dealt with the management of the MFT reserve funds, but I can't recall if they gave the MFT financial or legal advice.

Section 9: Complaints and appeals

77. Yes. In respect of appeals, there was an appeal procedure for grant applications. In the first instance and appeal would be raised with the trust staff. If the NSSC then refused funding a letter would be sent to the registrant. The registrant then had the option to progress any complaint to the Trustee board. I didn't play any other part in appeals other than being sat on those relevant boards. Appeals wouldn't be uncommon. Often a complaint/appeal, in respect of grant applications, could be resolved easily if the registrant was asked to provide more evidence for the NSSC to review.

78. MFT staff would have written to a registrant explaining why their application was rejected and explain that they could make an appeal if they so wished. The appeal procedure would generally be to re-submit their grant application with further evidence. If that was not accepted again by the NSSC, then it could be escalated to the Chief Executive or the Trustee Board.

79.

a) I cannot recall if a complaints process was introduced after the meeting.

b) I cannot recollect how many informal complaints were received. I do recall that it was generally a small number.

c) I couldn't put a figure on this. I do recall one or two complaints which were never fully resolved and were still ongoing at the end of my tenure.

80. I was in constant dialogue with a number of registrants, who often informed me of their concerns, which were predominantly about financial security, funding and the level of reserves, but there were also the issues discussed previously such as benefits, overall health etc. I felt I was aware of many of the issues that concerned people, and these often didn't change because the root cause of the issues lay in the insufficient funding of the MFT. As the issues arose we would bring them to the attention of senior management, mainly via the PG. The response was sometimes positive and sometimes indifferent, but Martin Harvey would always listen and would articulate that he understood and was aware of the issues that registrants had and felt. These dialogues were only during my tenure as a Trustee.

Section 10: The Partnership Group

81. The aims and objectives of the PG were to bring members of our community together along with those people directly involved in the running of the MFT and other organisations linked to our community (Haemophilia Society, Birchgrove Group). The PG was based around "user involvement" and there to directly facilitate constructive discussion between the registrants and those others in attendance. The PG was able

to raise the concerns of the registrants to the MFT staff and Trustees' attention and I truly believe it achieved those aims and objectives whilst I was a member. However, meetings could often create "difficult" and heated discussion points and were quite often unable to resolve all issues, primarily due to the lack of funding which acted as a barrier throughout the existence of the MFT. That said, having these open and honest discussions was pivotal in improving dialogue, trust, communication and future direction between both registrants and the MFT. I am proud of what we achieved for a short time with the PG – it certainly shows that with the right mechanisms in place then strides can be made. Even though the PG eventually petered out, I can honestly say that it wasn't for a lack of will or trying. The problems identified through the PG most often came down to the continual lack of funding, as those in charge at the MFT were often trying hard for the registrant community during this period. The MFT board could have been more robust in lobbying for more money but that was countered against the constant worry about continuation of funding by the DOH.

82.

a) When I became a User Trustee I knew there had been some talk of a PG existing previously, although I cannot recall exactly how active that had been, if at all. I believed strongly in concepts such as "user involvement" and registrants being "expert patients" when it came to their own care and well-being. Re-establishing the PG seemed like an excellent idea and I wanted to encourage it to be used by registrants. By 2004 the PG was up and running.

b) I can't recall the exact time period, but I was a member of the PG from approximately 2004 – 2006, before it started to tail off thereafter

c) Peter Stevens chaired the first couple of PG meetings, then it was suggested by Mr Stevens that I take over the chair position as I had experience of both sides, being both a registrant and a trustee. This would have been during 2004, it was a change that was agreed by all involved. As I recall I remained Chair until approximately 2006.

d) The number of people in the Group fluctuated from meeting to meeting, although there were a core group of attendees from around the country.

There was no formal membership, as all registrants were invited to attend as they wished but 15-20 attendees was quite usual.

e) Attendees were registrants, MTF staff, and the CEO, plus MFT trustees, the Haemophilia Society and Birchgrove Group were also invited to attend

f) The Birchgrove group was a more fluid organisation. Many of those involved in the Birchgrove Group came to PG meetings. The Haemophilia Society were invited but rarely attended. The only person who helped and attended was Babs Evans, who was a HIV Coordinator at the Haemophilia Society during this period. She came to events and PG meetings and was excellent to our community. I had nothing else to do with the Haemophilia Society because they weren't interested in the registrant community.

g) I believe we met every 3 months.

83.

a) There was certainly a climate of fear in the registrant community when it came to receiving letters about vCJD risk, as it was an additional blow to a community who were already suffering. I don't recall there being a "climate of fear" for registrants approaching the MFT at that time, as previously stated the CEO and office staff had always been open to dialogue with registrants. I know in later years this was not the case.

b) Generally the only people who met with the registrant community, via the PG for example, would have been Martin Harvey, Roz Riley and Peter Stevens. Some registrants had a better relationship than others with Martin and Peter, although as I've previously mentioned I felt that they were always accessible and open to dialogue. The MFT management/Board were running the organisation daily. However, I would hope that the Management/Board were aware of how the registrant community felt things were being managed and how things could be improved. Hopefully in some way, the dialogue between registrants and the MFT was able to inform and direct policy and effect change to benefit the registrants. Some registrant's seemed to have a difficult relationship with Jude Cohen during this period, especially over concern for changes to the Grants system. On occasion when communication wasn't good between registrants and the MFT then it brought problems to the fore.

c) I think it is unlikely that the MFT would have approached the DOH regarding the risk of vCJD to the registrant community. I'm unaware of any steps taken.

84.

a) After the length of time that has passed I am unable to recollect why there was anxiety at the way the Haemophilia Society managed the interview and selection process for Trustees. There was a breakdown in the relationship between many registrants and the Haemophilia Society, due to the historical systematic shunning of the registrant community by the Haemophilia Society

b) The Haemophilia Society were allocated a position on the Trustee Board, which they had a role to help fulfil. I recall there were continued difficulties in getting the Haemophilia Society to send representatives to meetings, such as the PG. I do not know why they were given these roles when they showed little interest in fulfilling them, in my opinion.

85. The lack of Government funding to the MFT was a constant concern to registrants, who often felt that the limited resources meant that support could not be adequately provided to the registrant community, even though it had repeatedly been demonstrated to Government that the needs and hardship of the registrant community were both increasing. I can't recall what the MFT's response was to these concerns on that day, but the MFT were aware of this discrepancy in funding and providing appropriate support. The MFT did not view itself as a lobbying body to the Government, seeing as though the Government held the purse strings and could go the other direction if pushed. Registrants disagreed, some vehemently, saying that they would rather see the MFT fight for better support for registrants, even at the risk of getting shut down doing so, rather than accept the pitiful support that was being given to the registrant community over the years.

86.

a) I cannot now recall what further action was taken, but I know that no further social worker was involved.

b) Yes, I felt a dedicated social worker, who was familiar with the registrant community's situation, was required. Registrants felt it very difficult to have to constantly go through the "normal" channels of health and social care, having to disclose their status and share their history repeatedly with new people. A dedicated social worker was important to a great number of the registrant community.

c) I think it was adequate but could have been better. The trustees, during my tenure, did bring a lot of skills with them.

87. I don't think the guidelines were always terribly clear which is why they were being revised. Increased clarity would have been beneficial to the registrants. Guidelines often became convoluted and included many parameters, this was generally required by the MFT due to having financial restrictions and really needing to specify what each Grant should entail. If suitable payment structures had been made to registrants from the outset there would have been little or no need for Grant Applications, or even for an MFT

88. This approach was deemed necessary by the PG because the reserve was substantial. Not only was registrant financial hardship increasing, but the Government were taking the view that with maintaining a reserve the MFT required less future funding, where in fact the opposite was the case. The MFT Board felt having a contingency with the reserve was good financial management, however it could be misinterpreted by the Government.

89. The MFT held at least 12 month reserves and whilst I felt some contingency was required, I thought the level of reserve was too high. This gave the Government an easy opt out of providing additional funding whilst there appeared to be a substantial reserve. I was never happy that the reserves were tied up and inaccessible in hedge fund accounts. I felt if there were to be reserves then they needed to be accessible at

very short notice. Whilst I'm no expert in this area, I felt the level of reserves should have been roughly half, or less, of what they were.

Section 11: Relationships with the Haemophilia Society

90. There was interaction between the MFT and the Haemophilia Society at CEO level but I am unaware of what this consisted of. I saw little involvement with the Haemophilia Society otherwise.

My own personal experience of the Haemophilia Society has been rather sad. All through my life I have felt extremely let down by the Haemophilia Society; the very organisation who should have been there for myself and my community throughout these terrible 35 years. My support and help came from the MFT far more than it ever came from the Haemophilia Society – yet the MFT were never set up to offer that kind of support.

The haemophiliacs who contracted HIV from blood products have been utterly rejected, neglected and ostracised by the Haemophilia Society. My community were like a "bad stain" on the Haemophilia Society. There was never any mention of us in their literature, never any support and never any lobbying on HIV. We were pushed away and forgotten, they did nothing for us – this from the very organisation that should have been there for us, shouting the loudest!

It upsets me writing this that they considered us with such disregard and so poorly that they couldn't even talk about my community, let alone fight for us. Whilst year after year those co-infected haemophiliacs were dying all over the country.

The only person who ever took the time and cared for my community was Babs Evans, she was a beacon of light and hope from within the Haemophilia Society whilst she was there.

91. Other than a lack of interest from Haemophilia Society, there were no issues that I was aware of between the two organisations during my tenure at the MFT.

Section 12: Other

92. In my opinion, the MFT was set up incorrectly in the first instance, so it was never "fit for purpose" from the start. The MFT endeavoured to do a good job, however, given the tools they were supplied with (inadequate funding and remit) then there was only so much that could be achieved. I always felt that the MFT staff were dedicated and gave their full commitment to the roles. I believe that if people like Peter Stevens, amongst others, hadn't been at the MFT, then the situation at MFT over the years would have been much worse.

Even though, during my tenure, I could not fault most of those involved in the MFT, ultimately I feel that it was unable to meet the diverse, critical and ever-changing registrant's needs. Unfortunately, the needs of the community evolved but the Trust did not ultimately move on to meet those needs. This was due to the MFT being woefully under resourced, it was due to the structure not being fit to meet changing demand/needs and it was explicitly due to being let down completely by Government after Government.

93. I began my role as a User Trustee having become interested in both my community and my health over the preceding years. During my tenure it was always tricky to maintain a balance between my role with the MFT and my feelings as a registrant. To undertake my roles and responsibilities correctly and fully, in terms of the role of a Trustee, I had to try to philosophically differentiate and consciously separate both my individual experience/hopes as a registrant from my responsibilities/duty as a Trustee. Of course, these two things became inextricably linked, from an ontological and epistemological perspective, and it was challenging to undertake the role but I committed to the role in the way I felt was most appropriate.

I. The role was best approached by attempting to build relationships and trust between people and organisations, mainly the registrants and the MFT. It would not have helped to be simply demanding of certain things, at the same time it was important that the feelings of the MFT community were highlighted and expressed in any given situation, moreover that people felt their voices were being heard.

II. I always found the people I worked with at the MFT to be cordial, friendly and committed to helping the registrant community. However, this is only in respect to the years I was a User Trustee (2003-2007), which is relevant to this whole document.

III. I always felt that the MFT did a good job in this period with the structural/financial tools that they were supplied with being always inadequate. It is worth noting also that the MFT were the only source of support, finance and hope for many registrants around the country. No other organisation represented us, cared for us or supported us – so, even though things were not perfect at the MFT during this period, it is worth stating that everybody else had completely forgotten about this community.

IV. In my opinion, the role of Peter Stevens was vital to the MFT having any ability to function in a professional and substantive manner. From my experience, without his dedication, commitment and personal knowledge the MFT would have been a lot worse off. I was also grateful to the staff at MFT, such as Roz Riley and Martin Harvey, who I certainly saw go above and beyond to try and support the MFT registrants, within the parameters that the Trust allowed.

V. I have also been very grateful for the support and knowledge that I have had from within my own community particularly through the Birchgrove group, the Partnership Group, and, more latterly, Tainted Blood. It is through this notion of self-support, shared experience and seeking the truth that we have remained strong even through the darkest of times. Even though many of the registrants are no longer alive I remember them with great respect and will continue their path with the knowledge and information that they have bestowed upon us over the years.

VI. In the years after I left my position as a user trustee, I noticed a gradual decline in the role the MFT were having with the registrant community. Pivotal staff seemed to be moved out of the MFT and there was much less engagement with the registrant community. There was also less flexibility built into the Trust support systems and, in the final years, it turned into an organisation that seemed to have lost the care and empathy that it once had, many years previous. Consequently, I no longer recognised the Trust and no longer cared to be involved with it and very seldom approached it for support. This meant that I had no formal means of support as a registrant – other than my own community.

VII. After speaking with a friend recently, they mentioned the whole situation around the MFT and stated "well, you can't polish a turd". It is a colloquial phrase round these parts, whilst rather crude it is the most appropriate analogy of the situation that I can think of. The Government caused this disaster in the first instance, then rather than supporting the registrant community properly, ended up leaving a real mess. At the beginning they established an organisation of little or no structure, with no design or built-in future and then they washed their hands of it. They left the organisation demonstrably underfunded and never went back to help. Those staff members and Trustees were doing their best to polish something that was impossible to improve, the registrants were doing their best to simply exist and all the time everyone involved in this whole sorry tale was not waving, but drowning.

VIII. The individuals, families and loved ones destroyed by this whole disaster have been irrevocably damaged by what happened. If that were not bad enough then the Governments response to this sorry affair has made the whole thing exponentially worse.

Statement of Truth

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

Signed.. GRO-C ...

Dated.......20 - 04 - 2021.......