Witness Name: Patrick Spellman

Statement Number: WITN3074002

Exhibits: None

Dated: 20th October 2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF PATRICK SPELLMAN

I, Patrick Spellman, will say as follows:-

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13th July 2021.

I have done my best to answer the Inquiry's questions as best as I can based on my recollection and knowledge of events, and with reference to documents that the Inquiry has provided to me. However, my recollection in relation to some matters is limited. I have done my best to make clear where this is the case throughout this statement. There may be other documents available to the Inquiry which clarify matters or which show my recollection to be inaccurate.

Section 1: Introduction

1. My full name is Patrick Spellman. My date of birth is GRO-C 1944 and my address is GRO-C in Hertfordshire. I have no professional qualifications relevant to the duties I discharged as trustee/director of the Macfarlane Trust (MFT), the Eileen Trust (ET) and Skipton Fund (SF).

Employment History

2. I entered the Home Civil Service in May 1963 as an Executive Officer in the National Assistance Board (NAB) which later became the Ministry of Social

Security (MSS) before merging with the Ministry of Health to become the Department of Health and Social Security (DHSS) from 1968 until 1988. At the NAB and the MSS I had authority, on reaching the age of 21, to make immediate cash payments at my government office and regular payments by printed Post Office order books to those who did not qualify for state unemployment benefit or pensions or whose income fell below minimum levels set by Five NAB Commissioners. I also acted as a local fraud officer as necessary.

3. From 1971 to 1980, as a Higher Executive Officer in DHSS London HQ, I oversaw implementation of the 1962 Hospital Plan for England and Wales (Command Paper No. 1602) within the counties of the then Trent Regional Health Authority in South Yorkshire, Lincolnshire, Nottinghamshire, Derbyshire and Leicestershire. This required obtaining the prior approval of health ministers and release of funds from HM Treasury for the building of nine new district general hospitals and expanding three university-based teaching hospitals across that health region.

4. From 1981 to 1984 I was a Senior Training Officer in DHSS HQ Staff Training Branch.

5. Later in 1984, as a Principal Officer in the DHSS Children's Division, I supported Health Ministers and Downing Street in their parliamentary and public responses to the Report of the Committee into Human Fertilisation and Embryology (chaired by Dame Mary Warnock) and set preparations in train for the creation of the Human Fertilisation and Embryology Authority in 1990.

6. From 1985 to 1992 I had policy and financial oversight of two government Youth Treatment Centres in Brentwood (Essex) and Erdington (Birmingham). They provided chargeable secure accommodation and education for UK local authorities' most damaged and dangerous young people aged 10 to 18 and, at no cost to the Home Office, for those convicted of murder or manslaughter under the provisions of S.53 of the Children and Young Persons Act 1933.

7. Following a major relocation of the Department of Health (DOH) from London in 1992 to the NHS Executive HQ in Leeds, I supported my Head of Branch and Professor Sir Michael Peckham in implementing a 1990 Research and Development Strategy for the NHS.

8. I entered the Senior Civil Service in 1994 and led a branch within the Public Health Directorate which supported the NHS Executive's Medical Director and the Chief Medical and Nursing Officers for England in producing guidance on clinical effectiveness. The Branch also funded all the Royal Colleges of health professionals to develop and improve clinical audit, the purpose being to help doctors, nurses and those allied to medicine to improve cost-effective research-driven outcomes through everyday evidence-based best practice. After devising plans for a new body, later created by the First Labour Government in April 1999 and known initially as the National Institute for Clinical Excellence (NICE), I retired at the age 54 on 1st January 1999. I have not undertaken any paid employment since.

9. The Inquiry has asked me to set out the experience that made me suitable for an appointment as Trustee/Director of the relevant AHOs. In particular, I felt that my earlier experiences at the NAB and MSS in helping financially deprived people escape destitution together with my later background in public health services might be of some value to one or both of MFT and ET.

Positions held at MFT, ET and SF

Macfarlane Trust

10. I recall that in early 2002 a DOH email canvassed interest from a dozen or so retired civil servants to replace two of the originally appointed trustees at MFT and ET. I attended a formal interview at DOH Skipton House in London in April that year. On 19th June 2002 Hazel Blears MP, Parliamentary Under Secretary of State (PUSS) for Public Health appointed me to serve as a trustee of both MFT and ET until 31st May 2004. In March 2003 she appointed me to serve as a trustee of the Macfarlane (Special Payments)(No.2) Trust until 31st May 2004. Sir William Wells, Chair of the NHS Appointments Committee, reappointed me to MFT until 31st March 2009. PUSS Dawn

Primarolo MP then re-appointed me until 31st March 2013. I recall that in 2011 DOH announced that it would not be making further new appointments to the MFT or ET. As the number of MFT Trustees declined, the MFT Board asked me to continue to serve up to 31st January 2015 and then at further intervals until its last six trustees left office on 28th February 2019.

Eileen Trust

11. As I recall, Health PUSS Ministers appointed all Trustees of the Eileen Trust.

12. Hazel Blears MP appointed me to serve as trustee from 19th June 2002 until 31st May 2004. Caroline Flint MP then reappointed all of the trustees of ET collectively until 31st March 2009. Anne Milton MP reappointed the board of trustees again to 31st March 2012 and then again to 31st March 2015. Jane Ellison MP re-appointed the board of trustees to 1st March 2018. Jackie Doyle-Price MP, PUSS for Mental Health, Inequalities and Suicide Prevention appointed the three remaining trustees (Peter Stevens, Russell Mishcon and myself) from 1st April 2018 until ET's dissolution on 28th February 2019.

Skipton Fund

13. I was asked by SF's Board of Directors to replace Gordon Clarke when his term of office expired in 2011. By then the scheme was being administered smoothly by Nicholas Fish and Shane Baker and the three devolved health administrations were supportive of the SF's arrangements for the victims of Hep C infection in their countries. I had no hesitation, therefore, in agreeing to step into Gordon's shoes.

Membership of AHO Groups and Committees

14. I was a member of the following AHO groups and committees:

- MFT Trustee Monitoring Group for Hilary Barnard's work leading to his Long Term Review Report in 2005. Along with the MFT Chair and its CEO and the Chair of the Haemophilia Society, entries in my personal diaries for 2003 and 2004 indicate that the Group met Mr Barnard four times at Alliance House to discuss his progress in inviting and receiving written responses to his questionnaires about beneficiaries', non-infected dependents' and widows' financial and other needs going forward after the first two decades of MFT support. My diary for 18 November 2005 records that I then attended a meeting at Alliance House with the MFT Chair and others whose names now escape me at which I was commissioned to produce an executive summary for the MFT Chair to use when he submitted Mr Barnard's' report and recommendations to DOH to support the case for much higher and sustained annual funding as set out in the Long Term Review Report. The executive summary was 551 words long, positioned at the front of Mr Barnard's 56 page report to engage Ministerial attention before DOH's senior officials studied and analysed his evidence-based findings and recommendations.

- MFT Employment Advisory Committee 2003-04. Staff matters, including recruitment and disciplinary issues, were the sole responsibility of the Chief Executive Officer in consultation, whenever appropriate, with the Board Chair. The Chair used this EAC to involve two trustees – myself and the non-executive Director of Finance – to consider other issues which would benefit the CEO and himself such as the generality of staff remuneration compared to other small organisations and to inform staff training and development, strategies. My diaries suggest I attended two meetings in 2003 and two more in 2004.

- MFT National Support Services Committee (NSSC) 2007-2013. I was asked by the Chair of MFT to fill a vacancy on the NSSC at a Board meeting in July 2007. This was carried by the Trustees' vote. The NSSC was chaired by the social worker Trustee and five others, three of whom were user Trustees or nominees of the Haemophilia Society. The NSSC awarded or declined single grant payments to applicants whose identities were redacted to avoid bias or favour. Supporting paperwork was often voluminous. The NSSC was assisted by a Support Services Manager and her team. They provided information supplied by the applicant, including household income and expenditure, history of previous requests for grants (including those of smaller value delegated to the Office) and supporting assessments by medical, nursing or dental practitioners, local authority social workers, benefits' advisers, debt counsellors or other disciplines allied to the caring professions. During my six or so years of membership the NSSC met monthly typically for 3 to 4 hours to consider applications. Papers were mailed to NSSC members by the Office to arrive on the Thursday prior to the next Monday's meeting. Another tranche of applications sometimes arrived by post that same weekend and even more urgent cases were tabled at the Monday meeting itself. Many requests were straightforward; others far from it. Most NSSC decisions were unanimous; others very occasionally needed the Chair's casting vote. Some set precedents for inclusion in amended Office guidelines which were updated periodically. A few favourable decisions in very complicated or unusual cases were only agreed on a "without prejudice" basis to ensure a case by case approach to future applications of a similar nature. Once MEFT payments were introduced there was a significant drop in applications before they began to rise again around 2014. When the Caxton Foundation was created, the MFT CEO changed the frequency of NSSC meetings from every four to every six weeks to ease workload pressures on his staff but urgent cases were always dealt with by 'round robin' emails. Appeals against NSSC decisions not to award a grant were considered by the same committee members. If upheld, disappointed appellants then had the right of further appeal to other MFT Board members. When User Trustees serving on the NSSC made an application he or she had to declare an interest and withdraw from the room until a decision was reached by others on the committee.

- <u>MFT Employment Advisory Committee</u> 2008-2010. I rejoined this Committee when it was chaired by the late GRO-A, a user Trustee, and I recall attending six meetings in that period.

- <u>MFT Grants Committee</u>. I was a member of the MFT Grants Committee from 2014 until the MFT ceased to exist in 2019. The process was similar to that described for the NSSC except that this Committee consisted of a Chair, myself and one of the Board's two user trustees. Meetings were mainly held by teleconference lasting about an hour and were attended by the MFT CEO, a new Director of Operations and a subordinate Support Officer to offer guidance on applications.

Other inquiries, investigations or litigation

15. I have never been involved in nor provided any evidence to other inquiries, investigations or criminal or civil litigation in relation to HIV, HBV, HCV or vCJD in blood and/or blood products.

Section 2: The Alliance House Organisations

16. I cannot recall any difficulties with working relationships between trustees/directors of the MFT, ET and the SF except on one occasion. In January 2015 the APPG on Haemophilia and Contaminated Blood published its report into the workings of the AHOs, which was based on its consultations with the beneficiary community using YouGov technology. On page 2 of its Executive Summary the APPG acknowledged its thanks to the MFT, ET and SF and its trustees for meeting with the APPG, providing additional written material and for agreeing to send APPG letters to their beneficiaries. However, on page 10 of the same Summary the APPG declared that it had (quote) "*also been approached, in confidence, by individual MFT trustees who themselves have expressed concern about the way the charity is run, and in particular its relationship with the DOH*". The APPG did not reveal the identity of the MFT trustees in question nor give details about their concerns but neither, as I recall, did APPG take up the matter subsequently with the MFT chair, CEO or Board of Trustees.

17. Based on my experience, I do not consider that there were disadvantages in being a Trustee of the MFT and ET whilst being a Director of the SF at the same time. Each operated without regard to the business affairs or needs of the others and none were privy to the others' papers nor did trustees of any one routinely meet the other two Trustee Boards. In meetings with the DOH the CEO of Caxton / MFT would be accompanied by each of the Chairs of the Caxton Foundation, MFT and ET/SF unless discussion / the business agenda was confined to one entity alone. Organisationally and cost wise the

advantage was that all three were serviced by the same Finance Officer and his / her assistant and had recourse to the same external audit company and legal advisors. I recall that this enabled the following (and resulted in staff and other modest cost savings):

- ET's 3 (or earlier 4) Trustees could contract in just one external member of staff (Mrs Susan Daniels) to act as caseworker/independent financial adviser;
- SF could employ just 2 members of full time staff with Mr Nick Fish as Administrator and Mr Shane Baker as his Assistant;

18. I only recall ever once making a reference to another AHO's operational business when I compared ET's bereavement grant to a more generous amount being paid by the MFT. ET Trustees readily agreed to match it.

19. The Inquiry has asked me a number of questions with reference to an email which I sent to Martin Harvey and Peter Stevens on 23 March 2004. It may be helpful for me to provide some context as to events in the lead up to this email. On 23rd January 2004 John Reid MP, Secretary of State for Health, announced the creation of a scheme of payments by April 2004 to sufferers infected with Hep C through an independent body to be called the Skipton Fund. I recall that it took MFT Trustees by surprise, and more so when it emerged – through a statement by Lord Warner on 5 February – that it had been agreed that MFT would administer the scheme with significant differences between the government payments to Hep C sufferers and the scale of MFT payments. In the lead up to reaching agreements with DOH the Chair of MFT called for trustees' views. I recall that I sent my initial thoughts by email on 23rd March 2004 [SKIP0000032_158] in an attempt to provoke senior trustees (Stevens and Clarke and CEO Harvey) into thinking deeply about the issues facing us all at the forthcoming April Board meeting. I do recall using the expression "long established public sector businesses". In reality, I recall that I did not consider the MFT and ET to be charities other than in name only since they were funded entirely by central government. Like quangos, they were at arm's length and were never closely supervised

by the Charity Commission during my time with the AHOs. DOH Ministers replaced all the AHOs in 2017 by transferring their beneficiaries to an arm's length special health authority, the NHSBSA. I also suggested that SF applicants would be disgruntled if they suspected that MFT and ET beneficiaries were receiving more favourable services within the same umbrella organisation. I also recall that by then both the Haemophilia Society and the Hep C Trust were critical vocally as were MPs representing campaigners about payments, for example the exclusion of certain widows from bereavement pay outs. It seemed to me that mixing MFT, nominally regulated by the Charity Commission, with paid Directors of a Fund answerable to Companies House had potential to give rise to difficulties. Messrs Stevens, Clarke and Harvey never responded to my email and I later accepted the MFT Board's corporate decision to proceed with the setting up of SF within Alliance House.

20. With the benefit of hindsight, I am glad that my forebodings were not responded to as they did not materialise.

21. It was not until 2011 that I became a Director of SF (some seven years after the email referred to above). As I have mentioned previously, by then the scheme was being administered smoothly by Nicholas Fish and Shane Baker and the three devolved health administrations were supportive of the SF's arrangements for the victims of Hep C infection in their countries. My view had changed by then and I had no hesitation in agreeing to become a Director of SF.

Relationship with Government

22. I was not aware of Mr Stevens' remarks on seeking specialist advice from me before he dealt with DOH officials. This does not accord with my recollection of his perception of my role since he was well served by his CEOs and other Trustees who accompanied him to meetings with Ministers and their officials. I did not know any of the officials other than Jonathan Stopes-Roe (of the Public Health Protection Branch) by former acquaintance in the NHS Executive (Leeds) during his short spell advising Ministers about the AHO

entities. I never had any one-to-one discussions with him about my membership of the MFT and ET Boards. Nor did I have any knowledge about the level of resources which those in DOH responsible for AHOs were able to command to enable me to perform such a role. Mr Stevens may, of course, have recalled my occasional habit of playing Devil's Advocate if outline MFT or ET Board proposals needed more forceful drafting in trying to persuade Ministers and officials to increase their financial allocations, or when commenting on first drafts of annual reports. But so too did all other Trustees as occasion demanded. That said, I do recall advising him to let me construct the executive summary to Hilary Barnard's Long Term Review Report as described at paragraph 14 above.

23. I cannot find any reference in minutes from the MFT Board meeting on 21 August 2006 [MACF0000020_102] to me urging caution in respect of 'overt lobbying' among members of parliament, on behalf of MFT. Nonetheless, I recall that it was my long held view that while political pressure needed to be consistently brought to bear on the government to increase funding to all in the beneficiary communities, MFT and ET should not overtly be part of it. I recall expressing that same view when Russell Mishcon brought his thesis entitled 'The Strategic Challenges Facing the MFT' to a Board meeting. I considered all Trustees to be independent of DOH influence in every respect. Overt lobbying had never been applied by any of those who went before me nor – apart from the confidential approach to the APPG referenced at paragraph 16 above – by those who served the AHOs thereafter.

24. The role of MFT and ET Trustees was set out in their respective Trust Deeds. Engaging directly with front and/or back benchers of the Houses of Parliament wasn't one of them and would, in my view, have diminished what little influence the AHOs had with their fund provider. Even the Long Term Review Report – commissioned and paid for by DOH itself - failed to lead the Minister, Caroline Flint MP, to offer more than an increase of £400K (11%) in government funding. MFT and ET's public and independent written evidence to Lord Archer's Inquiry and later to Lord Penrose's Inquiry in Scotland did not immediately result in increased DOH allocation either (though they obviously

did later when the Macfarlane and Eileen Trust Limited (MEFT) was set up). I recall my view being that sustained pressure on the Government needed to be led by the Haemophilia Society, their members, AHO beneficiaries and other campaigners engaging with constituency MPs. The proof of this, to my mind, is what happened in the end when Jane Ellison MP had to face hostile backbenchers in a series of Commons' debates where they persistently quoted letters of complaint from their constituents and demanded action.

25. From my experience and recollection, the AHOs always acted independently from Government. They consistently submitted bids for annual spending allocations which, apart from the post-Archer hike in payments, the DOH seldom, if ever, met in full. I expect that the Inquiry has already heard from many other witnesses how the beneficiary community and the AHOs suffered annual disappointment by DOH's lower disbursements. I know of no evidence which supports Alistair Burt MP's statement to Parliament that the relationship between the AHOs and DOH Ministers and their officials was "*too cosy*", nor Andy Slaughter MP's statement that "*The funds purport to be independent but they appear too close to the Department of Health*". [MACF0000022_028].

26. The Inquiry has asked whether I, or others within MFT, ET and SF, raised concerns and issues with DOH about the funding, structure, organisation or running of the AHO, or about the involvement of the DOH, or any other matter. I do not recall ever raising such concerns or issues myself. Those matters were raised frequently by the Chairs and CEOs on behalf of their relevant AHO entity. At a personal level, after my first appointment by the Junior Health Minister in June 2002, and for the next 16 years and 8 months, I do not recall having any personal dealings with DOH officials by letter, email, telephone or face to face meetings. I never accompanied any AHO Chair and/or others to meetings with Health Ministers and/or their officials. I did attend two meetings with DOH staff on 6 November 2009 and at a follow-up along with the Chairs and several other MFT and ET Trustees and our independent legal advisers. The purpose of those meetings was to explore and agree arrangements for disbursing the new non-discretionary/ discretionary payments scheme announced in the 2009 Government

Response to the Archer Inquiry Report before MFET was established (see the minutes of NSSC meeting held on 4 November 2009 [MACF0000128_051], agenda item 362.09).

27. In my view DOH oversight over the AHOs was light touch. I recall that at my first MFT Board meeting in July 2002 and at a couple more in 2003, a DOH observer was present. The CEO of the Haemophilia Society was also present. Neither of them shared their reporting back to their own organisations with MFT and I recall that by the end of 2003 their attendances at MFT Board meetings ceased altogether. MFT and ET sent copies of their annual reports and audited accounts to DOH and the Charity Commission for information and referenced them on the AHO websites. The SF acted similarly in respect of the DOH and UK's devolved health administrations together with filing fully audited financial reports and annual reports at Companies House. I cannot recall any occasion when the DOH, Charity Commission or Companies House challenged any of the matters covered in the annual reports and financial accounts. I recall that the AHO chairs and CEO would occasionally report that DOH officials *would* ask questions or cite examples from those papers in their face to face meetings about future allocations.

Section 4: Funding/Finances

28. Whilst a trustee/director of the AHO I was not involved in making funding requests to the DOH.

29. In my view the MFT and ET were grossly underfunded from their inception until the establishment of non-discretionary payments through MFET. I do not consider that SF was as underfunded but I feel that the initial rates of payments set for it by DOH and the devolved administrations to Hep C sufferers and co-infected haemophiliacs should have been far more generous before they were increased in the run up to the arrival of the arms' length Special Health Authority known as the NHS Business Services Authority. The post-Archer system of MFET non-discretionary payments doubled the tax free annual payment to primary beneficiaries to £12,800, which MFT and ET in

turn topped up through targeted bands of income-related discretionary payments. I recall a dramatic drop in applications for single grant payments for a couple of years during which, for the first time, primary beneficiaries and non-infected widows enjoyed their opportunity to obtain and control finances for themselves, as Lord Archer advocated. But it was not to last.

30. In my view, MFT, ET and SF being underfunded led to persistent beneficiaries' disquiet. I recall that concerns within the AHO organisations were caused by deficits in DOH's annual allocation to MFT for 2013/14 but significantly more so in 2014/15. I recall that the Board had to: (i) stop funding long standing and much appreciated separate men's and women's weekend and other social events; (ii) very reluctantly include SF and Caxton payments in the income of MFT beneficiaries when determining eligibility for one-off grants; and (iii) force some beneficiaries to look again to the Grants Committee if hardship struck again. I believe those steps, which I recall were taken with much regret, laid the seeds for growing frustration and accusations by campaigners that the AHOs in general and MFT especially were no longer fit for purpose. I believe this in turn led to the government's January 2016 consultation document "*Infected blood: reform of financial and other support*".

31. This consultation document suggested that such negative financial reforms were in prospect that the AHOs collectively submitted a robust response to the consultation in writing on 11 April 2016 and their CEO/Chairs met the DOH Director of Health Protection and Emergency Response soon afterwards to reinforce their opposition to the planned changes. I recall that the AHOs wrote to all their beneficiaries warning them about potential loss of income as well. On 12 April the co-Chair of the All Party Parliamentary Group (APPG), Diana Johnson MP, and around 50 other MPs debated the proposed loss of discretionary payments, and the intention to break index-linked MFET and SF regular payments and to introduce individual assessment to determine Hep C stage 1 eligibility for financial support. In July 2016 the DOH published a document entitled "*Infected blood: Government Response to Consultation on Reform of Financial and Other Support*" which I recall being pleased to see confirmed that it had decided not to proceed with the cost saving proposals

referred to above in the terms proposed having taken into account the consultation responses. It also confirmed that a single scheme operator would replace the 5 AHO entities in 2017/18.

32. The Inquiry has directed me to minutes from an MFT Board Meeting which was held on 20 January 2003 [MACF0000009_012] and has asked about me being asked to join a group to assist with a Long Term Review to mark an anniversary of MFT's establishment. The Inquiry has asked me why MFT decided at this stage to establish "different ways to use limited funds rather than seek to increase funds made available by the Department". To quote the full paragraph from item 07.03 of the approved board minutes for the meeting on 20th January 2003, it reads "*The Chairman saw the Review as being a means to establish new priorities for the Trust and look at different ways to use limited funds rather than seek to increase funds made available by the Department.*" That meeting took place 19 years ago at only the third Board meeting I had attended after joining the organisation seven months earlier. I do not know now, and I do not recall whether or not I understood then, what was meant by this. In 2005 the MFT Board submitted a very powerful business case to DOH ministers seeking to increase funds on the strength of the evidence based findings in the report of the Long Term Review.

33. The Inquiry has asked why, in 2011, I proposed that the MFT funds be ring fenced in order to set up a proxy form of life insurance. Lord Archer of Sandwell QC published his independent report into the infected blood scandal on 23 February 2009. Witnesses, including the Haemophilia Society, drew his attention to the inability of people with haemophilia and HIV to get any sort of life insurance or income protection for a mortgage. Accordingly, his report's 7th recommendation was that this could be achieved by government either providing the premiums or establishing a separate scheme for those in question.

34. DOH's response in a written Parliamentary Answer on 20th May 2009 said: *"the Association of British Insurers has assured us that insurers do not treat haemophiliacs or those infected with HIV or Hepatitis C differently from people*

with other pre-existing conditions. In all cases a person’s liability and level of premiums are determined through individual risk. The increased payments we are making will help people infected with HIV to meet higher premiums they may face”. I recall the late Martin Harvey, CEO, telling the MFT Board that he had complained orally to the DOH about the Minister’s parliamentary answer but that nothing came of this. I do not know whether his information was given at a NSSC meeting or Trustee Board meeting or whether it was formally minuted. In 2011 I suggested ring fencing funds from MFT reserves because there had been no feedback to any of our user Trustees in the MFT community that insurance policies were proving affordable as the DOH had predicted. At a special meeting of MFT’s NSSC on 28 November 2011, which was held to consider options for using some of the Trust’s reserves, I suggested ring fencing funds as a form of proxy life insurance for all to top up bereavement grants, which were not automatically payable to widows. My proposal did not find favour with other members of the NSSC. However, I can see that item 5 of the minutes with reference MACF000025_009 records that the NSSC determined to review the need to increase the bereavement grant paid when a primary beneficiary died.

35. The Inquiry has said that it has heard evidence that my proposal came to nothing because the premiums being quoted by the insurance companies were unaffordable, and has asked if this accords with my recollection. It does. I recall that in around 2015, daytime television was becoming saturated with what I considered to be scaremongering adverts about funeral costs rising far faster than inflation. I recall asking GRO-A, one of the co-infected user Trustees, to revisit DOH’s post-Archer statement about affordability by ringing an insurance company at random for a quote. I recall him telling me that on declaring his co-infection (HIV and Hep C) the call centre operative abruptly ended his call. From time to time I also asked Ms Daniels, the ET’s caseworker/ independent financial adviser, if it was becoming easier for people with HIV and/or Hep C to get life insurance, income protection or critical illness cover. I recall doing this because my mobile phone was being bombarded by scare stories about rising funeral costs but at the same time I

was hearing claims that premiums were, at an all-time low. Mrs. Daniels always told me that insurance premiums remained unaffordable.

Section 7: Decisions on Substantive applications

36. I recall that I expressed concern at an MFT Board Meeting in 2005 about a summer payment of £750 being made to all beneficiaries because there was a lack of guidance as to what it could be used for. Winter payments were recognised as helping to meet the higher costs of domestic fuel bills incurred to keep vulnerable beneficiaries warm during the colder months. I recall that I would have preferred the NSSC and the Board of Trustees to give directions as to usage such as, for example, using the payment towards respite breaks as opposed to routine holidays. As document [MACF0000014_26] shows, the Board Chair persisted in calling a vote for a summer payment of £750 to registrants and infected partners for any purpose they deemed appropriate. The vote carried 5 – 2 and became policy. However, after MFET came into existence along with the new improved discretionary MFT regular payments, I do not recall summer payments continuing to be made for long, unlike winter payments.

Loans made by the MFT

37. The Inquiry has referred me to a document with reference [MACF0000123_030] which it indicates are minutes of a board meeting which took place on 22 January 2008. Having reviewed the document I can see that these minutes are, in fact, minutes of a meeting of an NSSC, not a board meeting. The meeting on 22 January 2008 was only the second meeting of the NSSC that I attended. I do not recall my thoughts at the time and whether or not I agreed with any comments about there having been a degree of inconsistency in the granting of loans. However, given that it was only my second NSSC meeting, I do not consider that I would have been in a position to either agree or disagree with that comment. I do not recall having knowledge of why there had been inconsistencies.

38. My present reading of item 224.08 “Policy Issues”, Part 3 (in the document with reference [MACF0000123_030]) is that the Finance Officer wanted

NSSC Trustees to be aware that (i) recovery of loans made years earlier on a simple exchange of letters might prove difficult at a later date; (ii) the Trust's legal advisers needed to be consulted; and (iii) a different loans policy was operating in 2008.

39. When I joined the NSSC in November 2007 I found it to be very fit for purpose. I considered that its strengths were manifold. All information about the identity of the claimant was redacted to avoid prejudice and partiality, there were clear guidelines and three of its six members were user Trustees or had been recommended by the Haemophilia Society for appointment to the MFT Board. The chair was a very knowledgeable Haemophilia Centre social worker at the Royal Free Hospital in London and the MFT's medical trustee was copied into all NSSC Paperwork, giving advice on clinical issues as they arose. Although trustees never had access to beneficiaries' personal files nor to office files, the support staff were always ready and able to provide information about 'case law' or the background to individual cases if these were ongoing. As to weakness, there was no independent appeals mechanism. Dissatisfied beneficiaries were free to appeal to the main Board of Trustees if the NSSC, having reviewed any new supporting evidence, felt its decision should not be overturned. I recall that I found two other main disadvantages with the process. First, I thought it fostered a dependency culture. Some beneficiaries came back time after time with the same requests for small sums, for example, for children's school clothing or social activities. Second, I considered that there was an element of a postcode lottery to it. I recall that when DWP's Social Fund and NHS and local authorities' budgets came under severe pressure, arising from the 2008 financial crisis, some social workers and haemophilia nurses in some local authorities began to direct their clients to the NSSC on a regular basis while there was a complete absence of referrals elsewhere.

40. I resigned from NSSC in 2013. By early 2013, I was beginning to feel it was time for someone else to replace me after serving the NSSC since November 2007. Also, the Board's newest trustee was by that point already attending NSSC meetings as an observer. I recall a case arose by round robin for

making an immediate payment to someone whose application had already been rejected twice. I recall feeling that the case should not be decided by email but should await consideration at the next NSSC meeting but all the other members voted to approve the payment there and then. This influenced my decision to leave the NSSC. My resignation was without rancour, argument or recrimination. The minutes of the Board meeting on 29th April 2013 (item 608.13) record a smooth handover to another trustee [MACF0000024-047].

41. With regard to why I became Chair of the Grants Committee, I recall being taken aside by the Chair of the MFT before a Board meeting began on 12th May 2014. He explained that the terms of office of two trustees who were on the NSSC (one being the Committee's chair) had ended and they were being replaced at that meeting. Two other members of the NSSC who had sent advanced apologies for that day's meeting had told him they did not wish to serve on a reformed Grants Committee. That meant that apart from him and myself there were now no other Trustees with NSSC experience of the single grant making procedures and processes. The NSSC's former senior support services officer had also left the Trust. Her successor, now upgraded to the post of Director of Operations, would be introduced to the Trustees at that Board meeting. The Chair of the MFT asked me whether I would serve as the Grant Committee's first Chair, seeing as most of the new Board of Trustees also had full time jobs. I agreed, conditional upon there being: (i) no dissent from any fellow trustee; and (ii) my handover as chair once the new committee members had settled in. My appointment was recorded at item 683.14.2 ii) of the minutes from the meeting on [MACF0000026_057]. One User Trustee agreed to serve with me as did one of another recently appointed new Board member, who took the Chair from me at our fourth Grants Committee meeting. The User Trustee said that his commitments meant he could only serve for one year. The other User Trustee said he would take over at that time (but was never able to do so, I recall, because of subsequent work pressures).

42. I cannot recall why it was decided that the NSSC should be replaced by the Grants Committee. I understand there would have been detailed discussions between the MFT chair and CEO with the chair and members of the NSSC, of which by that point I had not been a member for 14 months. As to process, I cannot recall any fundamental differences other than a reduction in the number of trustees involved. In the days when there were 12 trustees on the MFT Board, 6 of them sat on the NSSC. When the Board was reduced to 6 or 7 trustees, 3 of us served the Grants Committee.

43. I do not know specific details as to the policy for inclusion of user trustees on the NSSC. I was not involved in the establishment of the first NSSC in 2004. From memory, it had five members, two of whom (including the chair) were appointed to the MFT Board by a DOH minister and 3 user trustees or nominees of the Haemophilia Society who were appointed to the MFT Board to input their first hand experiences about the financial and social needs of the community affected by haemophilia and HIV. Thereafter, user trustees always served on the NSSC and that practice continued when the new Grants Committee was formed ten years later.

44. Following the introduction of the post-Archer MFET non-discretionary financial scheme and discretionary MFT top-up regular payments, it became necessary to underscore that single grants could only be awarded in exceptional circumstances. These would typically be circumstances which a beneficiary could not ordinarily anticipate requiring expenditure which could not ordinarily be met from their normal income. One complication was that since the NSSC's inception some beneficiaries were receiving payments for Hep C infection. When the DOH stopped funding the MFT to the levels requested it became necessary (though unpopular) to have regard to regular payments made by other AHO entities. I have reviewed the minutes of the meeting which took place on 5th November 2014 (see [MACF0000022_008]) and can see that these show that the Grants Committee and senior office staff felt it would not be possible to set precise guidelines at that early stage and that it would be prudent to proceed on a case by case basis in order to gain

experience gradually. The application process obliged applicants to itemise their income from all sources and set out their household spending by categories such as rent or mortgage payments, utility bills and household shopping, etc. These details were declared on a standardised form which made it simple for staff and the Committee to see what proportion of an applicant's income, if any, exceeded outgoings. I recall that the aim was to find objective criteria leading to equitable and justifiable disbursements. One applicant might have had around £20,000 in annual uncommitted income while another, with similar income, might have had little or none to spare because they were paying off much higher mortgages, credit cards, bank loans and so on. I do not recall many referrals to the Committee by the staff but there were some from time to time – especially if the sum requested could be comfortably met by the applicant himself/herself without any obvious risk of hardship.

45. It is my understanding that staff decisions were reviewed by the Director of Operations and/or the Chief Executive before a decision not to award a grant was communicated to an applicant by telephone. All decisions staff reached were recorded and reported to the Grants Committee as a standing agenda item in the form of a consolidated schedule for Office grants.

46. The content of Office Guidelines was kept under review for several reasons including to monitor price rises in white goods etc over time. By way of example, they would be amended to record the cost of industrial strength washing machines needed by beneficiaries suffering from night sweats, or they might have been amended if the Committee had set a precedent by awarding a grant for circumstances which had never previously been encountered, such as to record the cost of private prosthetics when standard NHS disability equipment was unsuitable for an amputee.

Section 9: Engagement with the beneficiary community

47. I cannot recall why a small number of spot checks were required to verify the circumstances of individual primary beneficiaries at the end of the 2010/2011 financial year, as recorded at item 405.10 of the NSSC minutes dated 5th May

2010 (see [MACF0000015_048]). When a beneficiary was visited at home it was my understanding that this was usually at the request of the beneficiary community involving female social workers or service support staff to help them try to secure a favourable grants decision from the NSSC.

48. I had the same role as every other MFT and ET trustee or SF director when it came to engaging with the beneficiary community. Day to day engagement was by AHO staff through correspondence or in telephone calls. However, I recall that some ways in which I engaged with the beneficiary community of MFT and ET included:

- In the case of the MFT, receiving valuable feedback from user trustees;
- Attending two meetings organised with MFT beneficiaries in 2002 at a hotel in Manchester and in about 2008 in the West Midlands;
- In August 2005, I accompanied MFT's CEO to visit a beneficiary in her home - my witness statement signed and dated 30th April 2019 in response to the Inquiry's Rule 9 request dated 4 April 2019 refers to this;
- For the much smaller ET, our caseworker organised weekend gatherings of beneficiaries and trustees. I attended six of them at hotels in Nottingham, Leeds, Bournemouth, York, Bristol and Exeter;
- I accompanied ET's caseworker to a local authority case conference with one of the younger beneficiaries and her mother in Sheffield in July 2007.

49. All contact/engagements with those in receipt of SF payments were through staff in Alliance House. I had no personal contact with any beneficiary.

Section 10: Reform of the MFT, the ET and the SF

50. I did not approach the APPG at any time to speak in confidence or otherwise about the AHOs' affairs.

51. In the absence of any evidence to the contrary, I find it difficult to conclude that Alistair Burt MP's assertions about the leadership and operations of the MFT, and his conclusion that the MFT was unlikely to be able to be reformed,

were objective, realistic, impartial or even-handed. I say this because, as far as I am aware, he did not, especially not in the short time during which he himself was a DOH minister, make efforts to talk to, write to, meet or otherwise engage the leadership of the MFT or other AHO entities. I am not aware that he made efforts to get first hand responses to campaigners' redacted criticisms in letters, a debate at Westminster Hall in October 2013 to which the AHOs were not invited, or in the APPG's own enquiries when it could have confronted the MFT with the 'secret communications' from former trustees to test their veracity. Nor for that matter, did the Minister Jane Ellison MP, who consulted a great number of organisations and people – including a 20 minute meeting with MFT staff – but none of the chairs and trustees of the charities nor any of SF's directors.

52. I am not aware that the Minister or her officials ever attempted to try to defend the AHOs and MFT publicly nor make efforts to counter MPs' constant mantra that the MFT and the other entities were "unfit for purpose". My opinion is that that canard was initiated and adopted by a minority whose complaints were really about the schemes which the AHOs and MFT had to operate, and the funding made available to them, rather than about the performance of the entities themselves. Thus I consider that Mssrs. Burt and Slaughter MPs' comments that the DOH and the AHOs enjoyed too cosy and too close a relationship far from convincing. I consider that these comments are unrealistic and unsupported by hard facts.

53. As the MFT no longer exists I had to resort to the online Google search engine to research a written Parliamentary Answer given to Diana Johnson MP on 20th December 2018 by Jackie Price-Doyle MP, the Parliamentary Under Secretary of State for Health and Social Care. She said: "*I have written to the Macfarlane Trust on a number of occasions since 12 September 2018 asking for its plans with respect to any residual funds it held on closure. I also reminded the Macfarlane Trust that it must operate in accordance with its trust deed which states that the* ***funds can only be transferred to one or more bodies established for charitable purposes with similar, or the same objectives to its own i.e. providing support for people infected with HIV.***"

(emphasis added). The Trust's residual funds included outstanding repayable loans. The Terrance Higgins Trust met that criterion. The NHS Business Services Authority did not.

54. I do not know if any beneficiary's personal data was transferred to the Terrance Higgins Trust without that individual's knowledge and consent. I can see that the MFT Board's final letter to beneficiaries dated 12th December 2018 refers to the personal data and loan arrangements (see item 973.18 of the MFT Board meeting held on 1st November 2018 [MACF0000028-56]). This says "*…data subjects would not have a right to object but would need to be informed individually of such assignment*". However, based on recollections alone, I do not know what beneficiaries were told as I was not involved in the transfer of beneficiaries' data to the Terrance Higgins Trust.

Section 12: Other

55. While no management system is perfect or beyond improvement, I do consider that the MFT, ET and SF were well run. I would not have remained on their Boards for so long otherwise, not least when such a small group of staff and their Chief Executive (responsible for only 3 of the 5 AHOs (MEFT, MFT and Caxton but not ET and SF)) had to be overseen "virtually" by volunteer and unpaid chairs and trustees who were not themselves in day to day contact with their employees. In the space of 14 years trustees and staff at MFT were in the political spotlight, for example, there was:

- a Long Term Review (2004), which did not deliver beneficiaries' expectations;
- the establishment of the Skipton Fund (2005);
- Archer Inquiry (2009);
- MFET's new system of non-discretionary funding (2010);
- the creation of the Caxton Foundation (2011);
- the APPG for Haemophilia and Contaminated Blood Inquiry (2014)
- the Penrose Inquiry (2015);

- the DOH consultation exercise on reforms to the AHOs entities financial and support systems (2016);
- the transfer of operations and staff to a single scheme administrator by TUPE (2017), which left the MFT to close down its complex operations with only two employees – its CEO and Director of Operations.

56. I consider that there is external evidence which supports my views about MFT, ET and SF delivering a good service including:

- In 2009 the Government published its "*Review of the Support Available to Individuals Infected With Hepatitis C And/Or HIV By NHS Supplied Blood Transfusions or Blood Products And Their Dependents".* This Ministerial document addressed Lord Archer's proposal in detail and in Section 6.1 said "*Evidence given to the Archer inquiry from affected individuals suggests that applying to the existing charitable Trusts is viewed as demeaning for some individuals. Lord Archer argued that making ex-gratia payments through the DWP benefit system would give the Government direct responsibility for providing these resources.* However, ***the written submission from the campaign groups stated that they wanted the existing charitable Trusts to continue providing support.***" (emphasis added). Section 6.2 than said: "…*Secondly,* ***the mechanism for administering the schemes is well established through the Trusts and incorporates the necessary health expertise to determine eligibility****. This option (sic: transfer to DWP) was therefore not taken forward as a recommendation*" (emphasis added).

- The APPG Inquiry Report in 2015. This highlighted a 65% positive/neutral response by beneficiaries in relation to the AHOs. The report did not recommend their abolition either and acknowledged that a lot of criticisms about the AHOs from around 35% of respondents were due to the way they had been structured and funded by DOH.

- In announcing a single body to replace the 5 AHO entities, the July 2016 document "*Infected blood: Government Response to Consultation on*

Reform of Financial and Other Support" said, in sections 3.22 and 3.23, that a new body would retain "*not only financial* ***but other holistic support that many people have told us they so value under current arrangements***" but also "…***the elements of the existing financial and non-financial support current beneficiaries find so valuable"*** (emphasis added).

- A communications exercise undertaken by a user trustee which found as much satisfaction about the MFT's information sharing practices among beneficiaries as criticism by others.

57. I consider that in my time, the AHOs were served by remarkable people and experts: the MFT had four first class chairs and three very professional Chief Executives; a remarkable interim CEO who wound up the complicated business affairs of the MFT after its funding was transferred to a single provider in 2017; user trustees and other appointees nominated by the Haemophilia Society, many of whom were criticised by other beneficiaries for not delivering what campaigners wanted. At different periods three practising solicitors served as MFT Trustees. A solicitor and an expert independent financial advisor were long-term members of the ET Board. An Emeritus Professor of Hepatology and another Emeritus Professor of Medicine and Advisor to the UK National Institute of Health and Care Excellence (NICE) were among the Directors of the Skipton Fund alongside its first class Scheme Administrator.

58. The MFT, ET and SF always acted in line with investment specialists and legal advice when sought or needed, and met all their obligations to deliver fully audited accounts and annual reports to DOH, the Charity Commission or Companies House. They employed exemplary private sector advisers to deliver advice and support on benefits and other DWP matters and solutions to debt problems through independent financial advice. I do not recall any member of staff ever complaining to tribunals about unfair treatment, bullying or discrimination of any kind and I do not believe that they ever lost sight of the reason for their employment – the best interests and welfare of the victims

of the infected blood scandal. I thank them one and all for their dedication to the beneficiary communities, especially those who were the first point of call at the end of dedicated phone lines when beneficiaries needed "just to talk" or unburden themselves, listening patiently and sympathetically, sometimes for an hour or more, while deadlines came and went and demands for immediate action on reports and other urgent business piled up in their in-trays.

59. I am sure that more could have been done to extend the ranges of support offered had extra resources and staff been provided to the AHO entities by DOH. I felt it was particularly sad that those who lodged appeals against adverse NSSC or Grants Committee decisions could not have access to an external appeals mechanism similar to the expert SF Appeals Committee. Nonetheless, the internal appeals process whereby the MFT chair and trustees not serving on the NSSC or Grants Committee decided appeals was always objective, rigorous and even handed.

60. I have always held the view that there should have been a public inquiry at the time of the contaminated blood scandal, with appropriate compensation for the lives so cruelly lost and blighted physically, mentally and financially. I look forward to a time when those who remain find peace and final closure when the Infected Blood Inquiry completes its work.

STATEMENT OF TRUTH

I believe that the facts stated in this witness statement are true based on my recollections and the documents provided to me by the Inquiry.

Signed **Patrick Spellman**

Dated 20th October 2021