

Witness Name: RUSSELL MISHCON

Statement No.: [WITN4474001]

Exhibits: [WITN4474002 – WITN4474007]

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF RUSSELL MISHCON

I, Russell Mishcon of GRO-C Surrey GRO-C
will say as follows: -

Background and general questions

1. I was born on GRO-C 1948 and I am a practising solicitor, having qualified in December 1971.
2. I was a trustee of the Macfarlane Trust from the year 2006 to January 2014, having been appointed by the Board following national advertisement. I was also a member of the National Support Services Committee ('NSSC') during some of my time as a trustee and was also appointed to two Working Parties, both of which I was asked to chair. I also attended a few meetings of the MFT/Caxton House Liaison Committee. I have provided my years of service as a trustee but cannot recall my dates of service in the other roles save that the first Working Party, which I chaired, was in early 2008 and was to make recommendations to the NSSC in respect of the widowed community, and the second was in 2012, to consider the allocation of reserves.
 - 2.1 The Inquiry should know that I destroyed all my hard copy working papers relating to the MacFarlane Trust before the public enquiry was set up, due to my no longer being a trustee, the amount of space they were occupying, the fact that we intended to downsize and I saw no reason to hold on to them.

- 2.2 It also has to be said that it is now almost 8 years since I ceased to be a trustee and memories do not serve septuagenarians that well.
- 3.1 The role and responsibilities of a trustee of a charity surely need no description. However, being a lawyer, I was sometimes asked to help draft and/or proof read/amend letters or documents for the Trust.
- 3.2 The second Working Party, referred to above, was set up charged with making recommendations to the Board for the utilisation of a large part of the Trust's substantial reserves by providing additional financial assistance of a capital nature to its community of care, including widows. Examples that were in contemplation included property maintenance, longstanding debt issues, work and education programmes. The role of Chairman was to ensure that meetings were held regularly to achieve its objectives, that there was an agenda and that meetings were conducted in an orderly fashion.
4. I came to be appointed a trustee after I saw an advertisement for a trustee, which I believe was in the Sunday Times. As someone with severe Blood Factor XI deficiency, who had blood transfusions in the 1950s and 1960s, I was aware how very fortunate I was not to have been infected and considered that I might be a suitable candidate for the position and so applied. Following interview, as I recall with an independent assessor as well as some of the existing trustees, I was appointed.
5. I understood the function of the Macfarlane Trust to be the administration of funds provided to it by the Department of Health to its community of care, within the framework of a charity. The aim should have been to help those most in need, meaning financial need, but some of the policies of the Trust did not appear to me to take full account of financial need. The objectives were, however, well intentioned to provide inclusive support to the community of care, without being invasive into their lives. As I recall, the charity's lawyers, Berwin Leighton Paisner, provided new trustees with a comprehensive induction file but, beyond that, there was no 'training'.

6. I confirm that I have not provided evidence or been involved in any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood or blood products.
7. The Trust was not independent from the Government/Department of Health because it was solely dependent on them for its source of funds. I have described it as an instrument of the Government, but it was established as an independent charitable organisation. The one-time Chairman, Roger Evans, described the Trust as an 'arm of the government'. Whether an 'instrument' or an 'arm' of the Government, it should not have been and to be either is, I believe, contrary to Charity Commission guidelines. Whilst the Department of Health did not dictate policy to the Trust, other than by operating the purse strings and nominating two of the charity's trustees, neither did it, as far as I am aware, exercise oversight nor involve itself in day to day matters. It was also intimated, as I recall, that if the Trust sought to fundraise on its own account, any receipts would reduce the grant the Trust received from the Department of Health by an equal amount. Whether this was said at the meeting with the Department of Health, which I attended on 21 September 2012 (see paras 9.1 and 38), I cannot recall but it was definitely mentioned by the chairman at a board meeting, and possibly at more than one, sometime in either 2012 or 2013. It may even have been minuted in the Board minutes and certainly should have been. Other trustees will doubtless be able to confirm.
- 8.1 Did I consider the funding provided to the Trust by the government was adequate? The simple answer is 'No' and my dissertation for a Masters degree (awarded with distinction in 2008) examined the lack of funding in some detail. The title of my dissertation was:
"The Strategic Challenges Facing the Macfarlane Trust:
The effects of demographic change and lack of government funding on haemophiliacs infected with HIV-Hepatitis C by NHS administered contaminated blood products".

Compared with other comparatively 'wealthy' countries, the Government's response to those affected by the contamination was 'niggardly' according to 2 former Chairs of the Trust.

- 8.2 My research for the dissertation showed that the Trust was set up as a charity in March 1988, at the behest of the Government, to administer to infected haemophiliacs an initial fund of £10m. provided by the Government (equivalent to £8,090.00 per person infected). Lobbying by the Haemophilia Society, dissatisfied with such a response, prompted the Government to increase its ex-gratia payment, the following year, to £20,000 per person directly infected by contaminated blood, although infected partners were excluded. This and a subsequent 1991 capital payment were administered by the Trust, on behalf of the Government, but were established as separate non-discretionary trusts and did not form part of the Trust's charitable funds.
- 8.3 The subsequent 1991 capital payment, provided by the Government, amounted to almost £45m. (with distributions, set by the Department of Health, ranging from £21,500 to £60,500 depending on age, marital status and number of dependents) but was only administrable to those infected haemophiliacs who were willing to sign a waiver of their legal rights against the Department of Health. No legal advice was offered nor was there any recommendation to seek legal advice before signing. Whilst those infected knew, at this time, that they were HIV positive, none had been made aware that they were also HCV positive, yet the Government's waiver document referred to claims for hepatitis infection. The Government clearly knew something that it was not prepared to share with those haemophilia sufferers that had been infected, or their medical practitioners.
- 8.4 The Government, through the Department of Health, provided further sporadic grants to MFT in the 1990s, with annual grants commencing in the fiscal year 2001-2. The level of funding in 2007 was circa £3.75m., from which administrative costs of circa £300,000 had to be taken. This was not much changed from the previous 3 years when it was fixed at £3m. per annum but there was then, in addition, a section 64 grant to cover administration costs.

Most, if not all, trustees did not consider this could provide an appropriate level of 'relief' to the infected survivors and their dependents within the Trust's objects.

- 8.5 In 2006, before my appointment as a trustee, the Trust submitted a detailed Business Case to the Department of Health for substantially increased annual funding (from £3m to £7.5m) and for additional capital grants to its Primary Beneficiary community, as there had been no additional capital payments since 1991. The Business Case was based on a Long Term Review, commissioned by the Trust in 2002 and completed in October 2003 by an independent consultant, Hilary Barnard ('the MFT Long Term Review'). The Business Case fell on deaf ears, principally it seems, because of Treasury constraints. Trustees were advised that at a meeting with officials of the Strategy and Legislation Branch of the Department of Health on 10 December 2007, the then Chairman and Chief Executive of the Trust were advised that another reason for the 'rejection' of the Business Case was the absence of any discussion of 'empowerment' of the Trust's community of care.
- 9.1 In the absence of my files and with the passing of time, I cannot recall the number of times I raised issues at Board level but my direct contact with the Department of Health was negligible. From my computer diary, I note that I attended a meeting at the Department of Health on 21 September 2012 with the then chairman, Roger Evans. I do not recall what was discussed at that meeting, neither do I recall attending any other meeting at the Department.
- 9.2 Following my ceasing to be a trustee in January 2014, I wrote a joint letter with Elizabeth Boyd (a fellow trustee now unfortunately deceased) to the then Secretary of State (Jeremy Hunt) dated 12 February 2014 expressing our concerns about the running of the Trust. A copy of the letter is at WITN4474002. I no longer have a copy of the response but at WITN4474003 is a copy of a letter I wrote to Jane Ellison MP Parliamentary Under Secretary of State for Public Health on 27 March 2014. The letter to Jeremy Hunt refers to "other issues of concern" but, some 7 years on, I cannot recall what we were alluding to by that remark in that joint letter.

9.3 Whilst I do not know the exact date of the Board Meeting, Roger Evans, in his response dated 10 November 2019 to the written statement of Alan Burgess, refers, at paragraph 9, to a fellow trustee tabling a draft letter 'without notice and contrary to standing orders'. That fellow trustee was me and the draft letter is exhibited at WITN4474004. From recollection, standing orders were never published to trustees and consequently were only raised if it was in the chairman's interest to do so. I had prepared the draft in the hope that, as a Board, we would collectively sign such a letter to indicate our total dissatisfaction with the Department's indication of a reduction in funds. There was, as I recall, very considerable support for such a letter amongst fellow trustees, not just "two or three", but Roger Evans was adamant that, as Chairman, he would not sign such a letter and consequently, in the absence of the possibility of unanimity, it was not sent. I therefore take issue with the slant that Roger Evans presents in his statement.

9.4 For my dissertation, I wrote to the Minister of State for Public Health Protection, Dawn Primarolo MP asking for an interview and setting out a number of questions I wished to ask. The letter dated 5 March 2008, the questions and the Department of Health's reply dated 25 March 2008 are at WITN4474005.

National Support Services Committee ('NSSC')

10. The purpose of the NSSC, as I recall, was to consider matters delegated to it by the Board of Trustees and, in particular, to consider claims for discretionary payments from the community of care. Its composition was some 4 or 5 trustees from the main Board and was usually attended by the Chief Executive and the Support Services Manager. The NSSC, I believe, appointed/elected its chair, and it reported to the Board.

11.1 Papers for each application for financial support were circulated before the NSSC meeting. Sometimes, if there was some urgency, this was dealt with by round-robin email. Sometimes, with late applications, papers were tabled and read at the meeting. Consideration was given to each. Sometimes, in view of the nature

of the application, enquiry was made of the applicant's doctor(s), if no medical evidence had been provided, or referred to the Medical Trustee (Dr Mark Winter). The Trust, as I recall, dispensed with having a Medical Trustee, whilst I was a trustee, but I cannot recall when this happened. A vote was taken of those members of the NSSC present on each application. I cannot recall if the chair exercised a casting vote in the event of a tie.

- 11.2 The NSSC reported to the Board and their decisions had to be ratified, as I recall.
12. My view was that each application to the NSCC had to be treated on its merits and that each applicant had to show financial need. There were, however, guidelines, which the NSSC was expected to follow and, if the guidelines were met, the application was expected to be accepted by the NSSC, irrespective of financial need. I no longer have a copy of those guidelines and cannot recollect them. Whilst it was obvious to me that many members of the community of care never made applications to the NSSC, despite probably being in financial need, there were others who made numerous applications. It is perhaps the case that there were certain members of the NSSC, from time to time, who did not see the need to take financial need into account and that satisfying the guidelines was all that was necessary to secure their vote. So I cannot say, in all honesty, that there was always 'consistency and fairness of decision making'. I cannot recall if the changing composition of the NSSC affected this whilst I was a member.
- 13.1 The 'discretionary determination of need' was a difficult area and this did not apply only to the NSSC. The regular payments system was arguably unfair. For example, there was no differentiation in receipt for a single person living at home with parents with one living alone in rented accommodation. Neither was there much of a differentiation between a couple with no children and a couple with two children. There was no real assessment of need, despite the Long Term Review, which was undertaken in 2003, some years before my time as a trustee because, as I recall, some strident voices on the Board of Trustees argued that it would be inappropriate to rule out anyone, as all had been infected and felt entitled to some recompense and, indeed, had been receiving the regular payments for several years. Furthermore, it was argued that everyone with

haemophilia, who had contracted HIV and Hep C through infected blood, had medical conditions that incurred additional financial expenditure and, therefore, it was appropriate to make regular payments to them, without ascertaining if they needed financial assistance in order to meet that additional expenditure. It was also felt to be an invasion of privacy to meet with individuals/families from the community of care, in person, to ascertain their needs and, importantly, that the cost factor of doing so would be out of proportion to the financial return of ceasing payments to those whom the Trustees might determine were not in financial need. These were arguments that were strongly felt by a large number of trustees.

- 13.2 I was aware that Peter Stevens, the Chair of the Trust, when I joined as a trustee, was very conscious to ensure that financial need was taken into account in the Trust's disbursement policy and I fully supported that view, as evidenced by my subsequent conduct. MACF0000016_086 confirms Peter Stevens' stance and the legal advice proffered to trustees on the Trustee Development Day on 4 November 2006 was confirmatory.
- 13.3 Changes began to be made. In July 2007, the Board of Trustees made a distinction between those households earning above £30,000 p.a. (excluding regular payments from the Trust and earnings of any children) and those below, who received £57.00 per month more. I did question whether this was a sufficiently objective assessment of need.
14. I do not recall there being any definition of 'Exceptional Circumstances', which the NSSC had to follow. It was more a case of the committee agreeing that the case presented to them warranted 'exceptional circumstances', so as to justify a payment or that there were no such circumstances, so as to refuse an application. I readily admit that my memory may be failing me on this.
15. My recollection is that anyone, whose application was refused or who had a complaint regarding a decision or a decision-maker, could appeal to the Board of Trustees.

Loans and advances

16. As I recall, there were in existence when I became a trustee, a very few outstanding loans that had been made on an equity share basis. Other loans, depending on their nature, were secured on property, with borrowers being independently legally represented. I cannot recall if there were any unsecured loans, but there may have been, as repayments for all loans were, as I recall, deducted, by agreement, from the 'regular' payments.
17. In my time as trustee/member of the NSSC there were relatively few loans made and none which were equity share.
18. I am not aware of any criteria used to select recipients for the different types of loans/advances.
19. I am not aware of the Trust seeking legal advice and I, in my capacity as a trustee, did not. Where property was being charged as security for a loan, I believe that local valuations were obtained to ensure that there was sufficient equity to protect the Trust and the borrowers were always independently represented. The interest rate was, as I recall, usually at or below high street bank rates.

Working Relationships

20. As a trustee, I would say that the relationship with the Department of Health was generally business-like and sometimes fraught, because of the repeated refusal to adequately fund the Trust. This left me, as a trustee, feeling frustrated that we were not able to carry out the Trust's raison d'être in meeting the financial needs of our community of care. For me, it seemed obvious that the Department's civil servants had no idea, nor did they wish to know, how being infected with HIV and Hep C, on top of the physically debilitating condition of haemophilia, had blighted the lives of the individuals and their families. Those infected and still alive, were not expected to live more than a few years following the 1991 capital payment and no further capital payments have been made to the Macfarlane

Trust's community of care. I tried to persuade the Board of Trustees to take a tough stance with the Department and drafted a letter for consideration by the Board (see para. 9.3 above and WITN4474004) but to no avail because of Roger Evans' attitude, as Chair, which seemed to me to be one of appeasement.

21. I had, and believe most trustees had, an excellent working relationship with Peter Stevens (before his retirement as Chair of the Trust at the end of 2006/beginning of 2007) but he remained as Chair of the Eileen Trust, of which I was also a trustee) and with Christopher Fitzgerald as Chair, (following Peter Stevens retirement) until his retirement in 2012) I also had an excellent and warm relationship with Martin Harvey as Chief Executive. The same cannot be said of my relationship with Roger Evans, who became Chair in the spring of 2012. When Christopher Fitzgerald was retiring as Chair there was an external recruitment exercise, which was unsuccessful. I was asked by Martin Harvey if I would be prepared to stand in as Interim Chair until the process could be repeated. I reluctantly agreed to do so on the understanding that no other trustee would take on the role. Roger Evans subsequently put himself forward for the role and I withdrew, because I regarded it as important that any Interim Chair was unopposed. I recall, however, writing to Roger Evans and to Martin Harvey (Chief Executive) expressing my concerns that his standing for Interim Chair raised possible conflicts of interest, because of his trusteeship of the Caxton Foundation and other roles he held within Caxton. At the Board Meeting on 30 January 2012, at which I was not present being in Mexico, I understand that Roger Evans indicated that he was not prepared to wait until the following Board Meeting and was only prepared to act as Chair, not Interim Chair. I doubt if the Minutes of that Board Meeting would make reference to this. From that moment on, presumably because of the stance I took, he saw me as an adversary. As for Jan Barlow, who became Chief Executive of the Trust the year before I ceased to be a trustee, I was not particularly impressed by her attitude, not only towards me, as she seemed to be under the protective wing of Roger Evans.
22. I have no recollection of the working relationship between the Trust's senior management, the trustees and the Haemophilia Society other than to say that one of the Haemophilia Society's appointees to the Trust seemed to be

something of a pain in the side of several trustees, including myself, at Board meetings and at the NSSC, whilst he remained a trustee.

23. Again, I have no recollection of the relationship with the UK Haemophilia Centre Directors Organisation. My only contact with a Centre Director was with Dr Mark Winter, the Medical Trustee, with whom I had an excellent relationship.
24. The only clinician I was in contact with was Dr Mark Winter, in relation to my being a trustee of the Trust.
25. My only connections with other Alliance House Organisations were as a trustee of the Macfarlane Trust and Eileen Trust and being for a short time on the Macfarlane Trust/Caxton Liaison Committee.

My dissertation

- 26.1 There was concern at my observation within the dissertation that the trustees were likely to be in breach of their fiduciary duties, even though I had stated that the Trust's lawyers' opinion needed to be obtained.
- 26.2 One of the recommendations in my dissertation was the taking of legal advice on whether there had been a breach of fiduciary duty and this was implemented. Other recommendations were of a strategic nature. There were changes, as I recall, in the regular payments policy but I cannot be specific and, whilst there was no individual assessment of need as I had proposed, changes were made to the annual census of the community of care. I also have a recollection that designated funds were established to help beneficiaries and/or their dependents to start up a business or to leave home and to provide for empowerment projects.

The Archer Inquiry

27. I recall being heavily involved in reviewing the Trust's Objects clause following the Archer Inquiry Report, including liaising with the Trust's lawyers on an application to the Charity Commission for a cy pres scheme, but I cannot recall

the detail as I no longer have my files. I have however had sight of a Note I drafted which is at MACF0000015_045 as well as the sought after changes at MACF0000015_044. I have no further information.

28. In all honesty I have no recollection of the impact on beneficiaries of the payment changes that were made following Archer.

Working Party

29. There were two Working Parties I was involved in. The first sought to deal with, among other things, the widowed community and the second with the utilisation of reserves. Each was made up of trustees from the main Board, who I believe, but cannot be sure, volunteered and who were assisted by the Chief Executive. It reported in the first instance to the NSSC.

- 30.1 The first Working Party made the following recommendations:

that there should be no distinction between the non-infected widowed communities;

that the widowed would receive regular payments for 6 months and for a further 6 months at a reduced level, following an assessment of financial need by the NSSC having regard, in particular, for those with dependent children;

that the widowed with disabilities would be given 3 months' notice that their additional monthly payment reflecting their disabled status would cease;

that a designated fund of £35,000 be established (to be reviewed and, if appropriate, topped-up annually) to enable primary beneficiaries to empower others as well as themselves (£10,000 to cover the expenses of a primary beneficiary driven volunteer team and £25,000 as a fund for empowerment projects);

that a designated fund of £100,000 (to be reviewed and, if appropriate, topped-up annually) for dependents leaving home, setting up a business etc. which was to apply to both recent past and present dependents;

that the summer payment be increased.

30.2 As for the Working Party on the reserves, I refer to paragraph 3.2 above. There were 4 meetings of the Working Party and at WITN4474006 is a copy of my written report to trustees on the Working Party (taken from my computer dated 16.4.2012) together a copy of the letter sent to 'members' in April 2012. The principal recommendation was for an independent body to visit those households who wished to participate in the reduction of the reserves and had a requirement for a capital sum.

30.3 I have no recollection of how the recommendations in respect of each Working Party were received by senior management, but they were implemented.

31. I cannot recall whether the recommendations made in respect of each Working Party were implemented in full or only partially, neither how they were received by the beneficiaries.

Other

32. I believe I have already dealt with the question of my involvement in determining applications for financial assistance and support as fully as I am able to.

33.1 Under the chairmanships of Peter Stevens and Christopher Fitzgerald and the stewardship of Martin Harvey as Chief Executive, I believe the Trust was run efficaciously within the constraints of inadequate Government funding. I believe that all three did their very best to secure additional funding but the Government and civil servants in the Health Department were not interested in the Business Case put forward, probably because of the financial constraints on the Government at that time. The Trust tried its best to administer to its beneficiary community, but the community had been badly damaged, physically, mentally and emotionally, through no fault of its own and, with the Government unwilling to apologise and/or admit its culpability, this created a considerable number of very aggrieved people, who, whilst seeing the Trust as a lifeline, disliked receiving 'charity' from it. It was compensation they wanted and the Trust, as a charity, with its limited funds was only able to meet some of their needs.

33.2 I cannot recollect, during my time as trustee, any particular difficulties or shortcomings in the way in which the Trust operated or in its dealings with beneficiaries and applications for assistance.

33.3 I believed it was necessary for the Trust to investigate fully the needs of its community of care to ascertain the real, financial needs of individuals and families and that this should be done by a non-connected, experienced body making personal visits. It would have to be accepted that some beneficiaries would refuse such a visit on the grounds that it was an invasion of privacy and by others that have kept their HIV/Hep C status from family. But only by understanding the home environment in which each lived could their real financial needs be ascertained i.e. were they living in abject poverty, did their accommodation have central heating or was it or their furnishings in need of refurbishment/replacement etc. Equally, it could be ascertained if a beneficiary was living very comfortably, had well paid employment and might not need the regular payment and other benefits provided by the Trust. However, I accept that, since the great majority of the Trust's beneficiaries were undoubtedly in financial need of some sort, the implementation of such a nationwide policy, which would have had to be ongoing, would have been very costly and was likely to have had a negative effect on the Trust's limited resources.

34. I cannot think of any other information I have that is relevant to the Inquiry's Terms of Reference.

Transcript of oral evidence by Alan Burgess to the Inquiry Hearing 28 October 2019

35. I have already referred to this at paragraph 9.3 and the draft letter is at WITN4474004.

Written Statement of Alan Burgess No.2 18 October 2019

36. I have already referred to this at paragraph 9.2 and the letter to the Secretary of State for Health, Jeremy Hunt, is at WITN4474002. A similar letter was written at the same time to the Chief Executive of the Charity Commission and a copy of

this letter is at WITN4474007 I recall having a meeting with Alastair Burt MP but cannot now recall what was said or the exact purpose of the meeting.

37. I recall having such a meeting and the fact that Jan Barlow (the then Chief Executive), who would have been the subject of some criticism from us, did not turn up. I do not recall what was said at the meeting, but I think it follows from what I have previously stated concerning Roger Evans (see paragraph 21 above), that I would not expect him to respect other people's views. I do not recall him being particularly respectful to me or to others who disagreed with him.
38. I only attended one meeting at the Department of Health as a trustee. This was on 21 September 2012 (see paragraph 9.1 above). I would assume that it was usual practice for a Government Department to take minutes of such a formal meeting. I do not recall anyone from the Trust doing so.

Statement of Truth

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

Signed

GRO-C

Dated

22 January 2021