

Witness Name: Medora Ann Hithersay

Statement No.: WITN3206001

Exhibits: None

Dated: 22 October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MEDORA ANN HITHERSAY

I, **Medora Ann Hithersay**, will say as follows:-

Section 1: Introduction

1. My name is Medora Ann Hithersay. My date of birth is GRO-C 1937 and I reside at GRO-C, Hampshire, GRO-C. I have a big family in Hampshire and I often have study commitments in London. I became a Trustee at The Haemophilia Society ("The Society") in 2004 but I have not been active in The Society since I stood down as a Trustee in 2010. I am now only a member of The Society.

Section 2: The Macfarlane Trust

2. By way of background, the Government had set up the Macfarlane Trust ("the MFT"), as the Government had recognised patients with haemophilia that had been contaminated with HIV needed funding. However, they had never used the word "compensation" as to do so would be admitting liability. They recognised

though that patients had been infected through treatment and the NHS had provided that treatment.

3. The initial fund set up by the Government had £3 million funding. The MFT established a regime for each family to receive funding depending on the infected person's circumstances and the treatment required. There was a scale of monthly payments and initial payments which were designed to help ease their situation at the time of their application.
4. I was employed by the Trustees as Director from approximately 1997 to late 2003. Prior to my role at the MFT, I had worked in roles such as Regional Director of Scope. In this role I was responsible for support for the 100 plus local groups. I managed staff in eight regions through a management structure of local Regional Managers and staff with fundraising and social work experience. After leaving what was then The Spastics Society (now Scope), I did a Masters Degree in Business Administration before joining St Christopher's Fellowship as Director. In this role I was responsible for management of children's homes and special needs housing for young people leaving the care system.
5. After seven years in this role I retired and whilst looking in the Guardian jobs section, I saw an advert for the role of Director of the MFT and so I got in touch with them. It was not until I was appointed Director that I learnt about haemophilia and HIV and I became very committed to their cause.
6. I was appointed to replace the Director, who was also Founder Director of the MFT, John Williams. He was due to retire imminently. He had been at the MFT for eight or nine years by this point. At that time, in 1997, HIV contracted from contaminated blood was affecting a lot of people with haemophilia and they were dying very quickly. We were told medical professionals were on the cusp of a new treatment which would be very successful. This was the introduction of

combination therapies, which over time has greatly extended the life expectancy and possibilities for those infected with HIV to live a more healthy life.

7. There was a lot of anger about the situation in the haemophilia community in 1997. There was still a huge amount of secrecy around HIV and contaminated blood. In particular, I knew that haemophiliacs were angry as they had trusted the Haemophilia Centres that had recommended Factor VIII blood products to them. The MFT and The Society believed those treating them had been trying to do their best and they believed Factor VIII was a breakthrough. Some centres lost hundreds of patients, which must have been very difficult.
8. At the time the Directors and Trustees of the MFT were mainly ex-military post-World War Two veterans. The Chairman was the Reverend Alan Tanner **GRO-A**
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GRO-A The rest of the Board were experienced “financial” men, and my experience was that they were very guarded with the fund. They would rather have the money gaining interest in an investment fund than provide it to the families in need.
9. Once the Director had retired, I began as Director of the MFT. Perhaps the MFT Trustees did not realise they were bringing in somebody with a different view to them about how to administer the fund. My view was that the fund needed to be replaceable by Government and that we should be giving more generous individual grants to patients contaminated with blood products, for specific purposes. Previously the MFT had only rarely given individual grants. However, my view was that the Government was responsible for infecting these patients and we needed to find a way to provide grants to those in need.
10. When I had been Director of the MFT for two or three years, I cannot recall when, but it would have been around the millennium, I suggested we should apply for further funding from the Government. I was told by the Trustees that it would not

be possible because the MFT was a “one-off fund”. I did have a contact in the NHS at a senior level with whom I met with regularly and during my time at the MFT I was able to get two supplemental grants as a result.

11. I also employed a social worker to go out to families and assess their needs. This meant they were being properly assessed and their needs were being met more fully. I recall one lady was a widow of a man who had contracted HIV and she had also been cross infected. She had slept in the same chair, lying flat, for several years. Through the assessment, we were able to find her suitable equipment with a proper mattress to support her fragile condition. We tried to give people the best life possible under the circumstances and my view was that the money from the Government should be spent and not kept in an investment fund gaining interest. Unfortunately, my views regarding running the fund were not always supported by the Trustee Board.
12. During my term as Director of the MFT, I was also able to enable the establishment of support structures such as self-help groups, conferences, and bereavement counselling for wives who had lost their husbands through infection by contaminated blood. I also joined a working party with the Charity Commission which established the right for beneficiary users of a charity to also become Trustees of the charity. I held user group meetings, and we set up a committee of users. At the conferences we would discuss needs of the families regularly.
13. During this time, I was also Director for the Eileen Trust. The Eileen Trust was created for women who had received contaminated blood following haemorrhage, often during or after childbirth. They had received large blood transfusions, from which they had been infected. The Eileen Trust was managed under the umbrella of the MFT and the same staff group provided support to members of the MFT and the Eileen Trust. We would go and visit members and keep an eye on the children until they were 18. The members of the Eileen Trust were much smaller in number.

14. I remained Director of the MFT until autumn of 2003. By this time I was around 66 years old; the MFT considered retirement was a good idea and suggested it to me. When I left the MFT they replaced me with somebody whose views were more closely aligned with the rest of the Trustee Board. The Board seemed happier with that decision.
15. My experience at the MFT was that there was a perception that those infected should not need any more funding than the tax-free monthly sum they were already getting.

Section 3: Relationship between the MFT and The Society

16. During my time as Director of the MFT from 1997 to late 2003, the focus of The Society in terms of funding was slightly different. I encouraged the spending of the funds provided by Government to help meet the needs of registrants of the MFT.
17. The majority of the registrants for the MFT were also members of The Society, so they were aware of what each organisation was doing.
18. There was a good relationship between the MFT and The Society. The Society used to have an annual conference which I and Trustees from the MFT would attend. There was also the World Federation of Haemophilia Conference every four years which was an international conference for haemophiliac societies round the world. The MFT was a regular attender.

Section 4: The Society

Introduction

19. I first became involved in The Society in early 2004, as a result of one of The Society's Trustees calling to ask if I would be interested in becoming a Trustee.

Following that first phone call I applied to take up the role. Trustees at The Society were elected rather than recruited. Although The Society had approached me and asked me whether I would like to be a Trustee, I still had to be elected at the AGM. Members of The Society vote and Trustees can only sit for a maximum of two terms. That means The Society always knows when there will be gaps to be filled, and that the members can discuss who they would like to be a Trustee in advance of the position becoming vacant.

20. I remained a Trustee of The Society for six years, which was two terms, and the maximum time you could serve in one block. Once the two terms were concluded, you then had to stand down for at least a year. I felt, during the year's break where I would have to stand down, I would lose touch with the changing treatments available to those infected and the needs of families and children affected. For this reason, I did not seek a further term once a year had passed.
21. At The Society, once appointed, I jumped straight on board. I was given a lot of information about haemophilia and the treatment for it, and I also met with many parents of children with haemophilia. I was aware of the history of treatment and I visited groups around the country to build up my knowledge of the condition. This was similar to how I had built up my knowledge of HIV at the MFT. Although I had a considerable knowledge of HIV from the MFT, I had not met families of children newly diagnosed with haemophilia before I took on this role. I met haemophiliacs with HIV during my role as Trustee of The Society but not as a separate group. I knew that the MFT could provide those haemophiliacs with specialist support.
22. I had a broader remit relating to haemophilia at The Society than I did at the MFT. I was involved with providing support both for haemophiliacs that did not have an additional condition, and for those who had been infected. As I was doing a wider role I rapidly had to learn about treatment for young children diagnosed with haemophilia. We needed to support parents with the diagnosis and provide self-

help groups. There was lots of work supporting parents at the time and getting them together to discuss the condition and treatments.

23. During my introduction period, I was also given the background and history of The Society. I knew The Society was instrumental in campaigning for funding for those infected with HIV through contaminated blood products. At the time this was one of their big achievements. After the MFT was set up The Society did feel it was a huge achievement to obtain Government support and I believe they thought they could turn their limited attention and funds to other haemophiliacs.
24. I am not aware of any background pre-dating my role as a Trustee for The Society. As far as I am aware The Society believed at the time that Factor VIII was a very helpful treatment for haemophiliacs. It did help, but it also killed many of them.
25. I thought the introduction to The Society was good and I got a briefing from the female Director, whose name I do not recall. I explain the governance structure at The Society in more detail in paragraph 34 below. The Trustee Board was supportive and helpful.

Funding

26. Initially, at the time I was appointed, the surplus money from fundraising for The Society would go to families with young children with haemophilia, as this was the emphasis of The Society at the time. There was a perception that those that had contracted HIV were being dealt with by the MFT. I believe this continued until there was a realisation that so many haemophiliacs had contracted Hepatitis C through contaminated blood products. This then became an overriding area of concern.
27. When I was appointed as Trustee at The Society, I found the Board to be much more realistic and sympathetic than at the MFT. This was because the Trustees

either had haemophilia themselves or had children with the condition. Therefore, they had a far greater understanding of the problems and issues faced than the majority of the MFT Trustees.

28. The money The Society had could be spent on those with haemophilia, and their focus was not on how fast you could gain interest on the fund, as at the MFT. We gave haemophiliacs their own voice and we were campaigning for a better deal for them. Those dying had died in awful circumstances; those living, lived in poverty. Those infected were denied the ability to work and have the life that they wanted for no other reason than unknowingly receiving contaminated blood products.

Campaigning for funding

29. When I first began as Trustee at The Society, haemophiliacs infected with Hepatitis C had no dedicated funding, whereas those with HIV did. I knew a lot of haemophiliacs with liver disease that died, whether that was due to having a failed liver transplant or from liver disease itself which may well have been linked to Hepatitis C.
30. We began to campaign for the emerging needs of the group of people who had been infected with contaminated blood. The MFT and The Society worked together to lobby the Government for compensation for those infected with Hepatitis C through contaminated blood products. It was felt that the MFT and The Society were stronger together. We were very active and there was an All-Party Parliamentary Group which lobbied for better funding and support.
31. This joint campaigning led to the development of the Skipton Fund in 2004. The Skipton Fund was created for those that had been infected with Hepatitis C.
32. There was a period thereafter when The Society thought "*at least it is recognised and there is some funding in place*", but The Society never lost sight of the

Government being liable for infecting haemophiliacs with HIV and Hepatitis C. There were a lot of upset and angry users and parents in The Society at the time and they were lobbying for good and safe treatment to be used.

Trustee Board

33. I found The Society's Trustee Board much more user-friendly than the MFT Board. Many of the Trustees for The Society had haemophilia themselves or they had some kind of link with haemophilia, whether that was having a child or a partner with haemophilia. That was how it was when The Society was founded and how it remained when I joined The Society.
34. In terms of governance, there was a Trustee Board, a Director, then senior staff under the Director. There were also separate departments, such as finance and fundraising. There was never a big staff structure. The Director at the time was a woman and she was very good. I am not sure why she left the organisation but she was very organised and she certainly knocked The Society into shape. The Trustee Board had around 10 or 12 members and The Society made policy decisions through the Trustees. There was no regional set-up but there were a large number of local societies which would come together each year for The Society's AGM.
35. There were one or two Scottish Trustees on the Board. There was a separate Haemophilia Society in Scotland but they were affiliated and linked with the English Haemophilia Society. There was the World Federation of Haemophilia too and we all went together to the Conference they organised every four years. We had very close links as a Trustee Board. We were an autonomous organisation under charity law and we had a separate Government structure to the Haemophilia Society in Scotland. The Directors of the two societies met regularly and so there was lots of cross-fertilisation of ideas between the two organisations.

Campaigning for the Inquiry

36. During my time at The Society, I concentrated on making the members' lives better. There was growing activity with campaigning for a new Inquiry. When I joined the MFT in 1997 we knew that some people had contracted Hepatitis C but that was not the main issue at the time. They did not realise at that time that practically everybody had Hepatitis C. When I left the MFT at the end of 2003, the impact of Hepatitis C on registrants was still not fully recognised; it also took a while for The Society to recognise the impact on its members. It became a significant issue and concern for both the MFT and The Society.
37. Once people had realised that many of those infected with HIV had also contracted Hepatitis C, and others had contracted just Hepatitis C, there was a lot of activity. Hepatitis C was not given the same weight as HIV until considerably later.
38. We then started actively campaigning for an Inquiry, in particular with the All-Party Parliamentary Group. Lord Alf Morris lobbied for a formal Inquiry, both in Scotland, which was the Penrose Inquiry, and also the Archer Inquiry in England although this was considerably later on.
39. Both The Society and the MFT were actively campaigning for the Penrose Inquiry as we believed we had a better chance of an Inquiry in Scotland. There seemed to be a greater sympathy in Government in Scotland and an increased openness to examine the cause of the scandal. We did have the All-Party Parliamentary Group in England but there was a historical reluctance in England to recognise the liability or extent of the contamination earlier.
40. After the Penrose Inquiry, The Society and Lord Morris actively campaigned for the next Inquiry in England, which was the Archer Inquiry. This was after I left The Society.

41. I was a Trustee at the outset of the campaign for the Archer Inquiry in around 2009/2010. As part of the campaign, the Trustee Board met people in the Government and campaigned for the inquiries. The Trustees were not just figureheads; the Trustees at The Society were very hands-on compared with the MFT. They were often involved in driving forward policy and campaigning. We were also responsible for keeping members updated with the monthly newsletter and regular conferences.
42. All the Trustees were very involved in The Society's aims. The members knew what we were fighting for at the time. The Trustee Board meetings often focused on campaigning, how we would campaign and who to. The Board would be directly involved in writing and approving the letters which would be sent out by the Campaign Director – it was all Trustee-driven.
43. At the time we relied on the Campaign Director and the Director to deal with the media. I was at The Society from 2004 to 2010 and social media was less prevalent then. I had never had to deal with the media or give evidence in either of the other inquiries, although I attended meetings about them. My second term at The Society was up in 2010 but I remained involved as a member.
44. I still receive invitations to conferences and the monthly magazines. It was only in the last two to three years that contaminated blood featured a lot in the magazine. Prior to that it was mostly about what The Society could do to help young parents and support available. There has been a change in the level of information available in the monthly newsletter and magazine now. It is focused on the build-up to the Inquiry and the developments with it.

Section 5: Other Information

45. The Inquiry is important to me because I am still extremely concerned that justice needs to be done. I am not driven by compensation, as I have not been directly

infected or affected by contaminated blood products, but I do want to know what happened and if the Government and the NHS were liable. I also want to know whether there was a cover-up and if there was, I believe that it should be exposed. I believe there should be a proper apology to the families of the people who have died as a result, because those people deserve that.

46. In relation to the Archer Inquiry, I was not close to or involved with it but I would say that it appeared to be a whitewash. The Inquiry had no teeth. Recognition was as important as money for the registrants of the MFT and the members of The Society. They wanted proof and acknowledgement that people knew about the contaminated blood products and kept treating patients anyway.
47. The Directors of the Haemophilia Centres across the country were very dedicated in my view. The dilemma they were facing must have been dire if they did know that the blood products were contaminated. However, we must consider that there was so little known about HIV at that time. Now we know so much more about it. It was not the case that within weeks of treatment patients became sick; AIDS did not appear overnight. There was a pattern where people were initially sick with flu-like symptoms and then some time later they became seriously ill. It was only then that the link between blood products and HIV was made.
48. During my time at the MFT I was aware that groups of registrants went to the solicitors that the MFT recommended. I recall that there was some difficulty in obtaining the medical records of the registrants. This continued when I became a Trustee of The Society, as members of The Society were also having difficulties obtaining their records. Assistance with obtaining the records was needed and that was part of the need for litigation; to force healthcare bodies to disclose those records to the solicitors of the members.

Statement of Truth

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

Signed GRO-C

Dated..... 22nd October 2019