

Witness Name: C Walton
Statement No: WITN1589001
Exhibits: 0
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CLAIR WALTON

I, Clair Walton will say as follows:

Section 1: Introduction

1. My name is Clair Walton. I was born on the **GRO-C** 1961 and I live at
 GRO-C
2. I make this statement both as an infected partner and as the widow of Bryan Walton (deceased) who was infected with HIV and Hepatitis C as a result of receiving contaminated blood products
3. **This witness statement has been prepared without the benefit of access to my full medical records or Bryan's full medical or educational records.**

Section 2. How Infected

4. Bryan was born on 21 April 1958. He had severe Haemophilia A with less than 1% clotting factor, and was infected with HIV and Hepatitis C through the use of contaminated Factor VIII products and I was infected by my

husband. My husband was treated with Factor VIII products from 1970s until his death on 13 March 1993. He attended the Haemophilia Unit in Coventry, Haemophilia unit at Wonford Hospital, Exeter and finally the Oxford Haemophilia Centre. He also attended Stratford upon Avon former infectious diseases hospital while boarding there age 4 to 11 and Lord Mayor Treloar School when he boarded there age 11 to 16.

5. Schooling was difficult for Bryan in the 1960s because of his condition. When he was 4 and a half years old he was sent as a weekly boarder not to a school but to a hospital in Stratford upon Avon – the former Infectious Diseases Hospital. It was only 10 miles away from where Bryan lived in Leamington Spa and these days would take no time at all in a car, but back then, his parents had to rely on volunteers to drive him there on a Monday morning and bring him back again on Friday.
6. Bryan told me that when he due to go to secondary school Warwickshire County Council refused to take responsibility for him and informed his parents that he must attend the Lord Mayor Treloar School in Alton, Hampshire where he boarded during term time and returned home in the holidays.
7. Bryan always fought for his independence and he hated to be seen as a victim.
8. In early 1985 Bryan was called into Wonford Hospital in Exeter and during that appointment he was told that they were going to do a blood test but I am not sure if he was told what the test was for. Approximately six weeks later I went back to the hospital with Bryan and he was told he had tested positive for HTLV3 (later known as HIV) which leads to AIDS and that he had 2 or 3 years left to live. Whilst they were telling Bryan about HTLV3 (HIV) and the prognosis to AIDS the nurse passed me rubber gloves to protect myself, it was all very strange.

9. No real Information or advice was provided to Bryan or me regarding his infection or how to manage the infection or the risks of others being infected, other than he should wear condoms if having sex. There was no counselling or support given. We just had to go home alone to digest what had just happened. I believe that adequate support, advice and information should have been provided to both of us as soon as Bryan was diagnosed as HIV positive.

10. I attended Coventry Hospital in or about June 1987 for a HIV test and was later told "it looks as it might be positive" and that I had probably sero-converted but I had to wait for a second test to confirm the results. I went numb and floated through the next few weeks in a strangely numb state. The hospital told Bryan that my second test had come back HIV positive when he attended his own appointment but they did not tell me directly.

Section 3. Other infections

11. Bryan also developed non-Hodgkin's lymphoma which he was told was a development of HIV into what was known at the time as 'Full Blown' AIDS. Bryan did ask about his Hepatitis C status a short time before he died because that was when other people started finding out they had the virus. If Bryan was told he had Hep C he did not tell me. He did say to me "what does it matter?" For Bryan Hepatitis C was just another infection and nothing could be worse than having AIDS. I did not know that Bryan actually had Hep C infection until years after his death.

12. When I first met Bryan he told me that he had been told by doctors that over the years he had been subjected to small doses of hepatitis through his haemophilia treatment and that he had naturally developed antibodies. It was relayed to him as if this was a good thing. As far as I know we had no information at the time about vCJD.

13. In 1999 I started to develop infection on my face which devastated my confidence as my whole face irrupted bright red and was covered with spots. Up until then I had beautiful skin and freckles. I am left with scars on my face from the condition. My health declined due to the advancement of HIV infection and by 2003 I was diagnosed as having what was known as 'Full Blown' AIDS. I developed an infection in the lungs, Pneumo Cystic Pneumonia (PCP) and an infection in the brain Cytomegalovirus (CMV). I came within days of death and was admitted into the Royal Free Hospital AIDS ward. My immune system was dangerously low because of my HIV infection; I take anti-retrovirals to keep the virus under control and to prevent opportunistic infections. I have suffered a variety of side effects from the medication including chronic diarrhoea, and have lipodystrophy, fatty liver and excess fat around my vital organs. I have to take anti-retroviral medication to keep me alive for the rest of my life. I am currently being investigated for high levels of calcium in my blood due to Hypo parathyroid, an abnormality of one of my parathyroids. This has caused a reduction in my bone density.

Section 4. Consent

14. I believe that Bryan was tested without his knowledge but I have no proof of this. This is just what I believe. I am not sure what happened before we became a couple. As a child, his haemophilia care was under Coventry Haemophilia unit, brief periods in hospital at Birmingham Children's Hospital, and in term time before age 11 in Stratford upon Avon, and between 11 and 16 at Lord Mayor Treloar School. As an adult, he was cared for by Coventry Haemophilia unit, a brief period (1984/5) at Wonford Hospital, Exeter, back to Coventry then Oxford Haemophilia Centre in the early 1990s. I do not know what happened when he was treated in Exeter, Devon but that was around the time when Haemophiliacs started finding out about their infections.

15. I now think that he was tested for research purposes but I did not think it at the time. Back then we could not even imagine that patients could or would be used for research. However, looking back on how I became HIV positive I now recognise it is very likely that both Bryan and I were used for research purposes.
16. The reason I believe that I was used for research purposes is because as a newly married and healthy young woman with a HIV positive husband I was an excellent subject for the study of how HIV spreads. Knowing that other people in similar situations to Bryan and I were definitely used for medical research strengthens my belief. I vividly remember that when they tested Bryan for HIV, they did not test me. The hospital showed no urgency to conduct those tests and it was not until after they told Bryan he was HIV positive that they tested me.
17. In 1986 we went to hospital for help and advice about having a baby and were offered monitoring that was strictly for HIV and had nothing to do with helping me conceive. That for us was an indication to us that we were not doing anything wrong. Instead of saying that in our case trying for a baby is really dangerous and we should not even attempt it, they just told us *"this is not a good idea, but we will monitor you."*
18. I am absolutely convinced that I was tested for research purposes from then on. I never made any real effort to talk about it as at the time we were just digesting all that had happened to us. The fact that I was negative, and we'd had unprotected sex for years prior to Bryan's diagnosis, lead us to believe that I was unlikely to catch it. We were convinced that, if we were doing something wrong, the hospital would tell us. The fact that they didn't sent positive signals to us to go ahead.
19. Today it is clear to me that I was just a study to them and that is why the Haemophilia Unit failed to provide us with real advice or support. Only a few months ago I found out that there were documents outlining the framework

of studies on partners of Haemophiliacs infected with HIV dating back to mid 1980s. I would be very surprised if I was not tested on without my knowledge.

20. The circumstances under which I became infected with HIV should be looked at again. Based on all the information now available, I refuse to believe that I became infected due to the NHS' incompetence. I think it is far more sinister than that.

21. Neither Bryan nor I were aware whether we were tested for Hepatitis C. When I was confirmed to be infected with HIV I continued to be a patient at the Coventry Haemophilia unit until the 1990 legal case. The solicitor we were using at the time, Peter Jones, consulted Dr Rizza at Oxford Haemophilia Centre about the treatment both Bryan and I had received at Coventry. Dr Rizza told him that he would have dealt with my case differently than Coventry had, so after that we moved to Oxford Haemophilia Centre. However, when Peter Jones asked Dr Rizza to make a formal statement about the problems with my treatment under Coventry Dr Rizza initially refused. Dr. Geoff Savage, from St Thomas's Haemophilia Centre wrote a report condemning Coventry's treatment of me under Dr Shinton.

Section 5. Impact

22. As stated above Bryan was a severe Haemophiliac with factor levels of less than 1 %. I met Bryan on 21st November 1978 (I was 17, and Bryan was 20). I thought that he was quite a character. When we first started dating Bryan did not mention his condition. His friends knew but it was never a big deal.

23. In July 1982, we became engaged. We bought a 3-bedroom semi-detached home in Leamington Spa for £23,000. I was so proud. We put down a £2,000 deposit and the rest was funded by way of a mortgage. We had set

the date to be married and I would move in after we married. This house was going to be the start of our future and our family.

24. On 21st May 1983 Bryan and I got married. We were young and in love and were starting out with all the joys of young newlyweds with a long life ahead of us. As far as we knew we had a bright and happy future together. We looked forward to creating a beautiful home and garden. We chatted and dreamt of having children. We were aspirational, determined and optimistic, and were already establishing good careers - there was nothing stopping us from fulfilling our dreams and having a wonderful life together.
25. In late 1983 I applied for a senior role after qualifying as an Archive Conservator. I applied for two senior positions: one in Lancashire and one in Devon. I was offered both jobs and I chose Devon and so we had to move. My responsibility as Senior Conservator was to care for the conservation of the entire Devon archives - one of the largest UK collections held in the County Records Office in Exeter.
26. Bryan and I looked forward to continuing our dream, a better house, great careers and eventually a family in a beautiful part of the country. Bryan joined me in Devon later in 1984.
27. Bryan was diagnosed with HIV in early 1985 and very soon we began to understand the impact and nature of HIV mostly from the heavy coverage in the news. It was a terrible time. The climate of fear and discrimination around AIDS was mounting in the media. It was alarming. The thought of anyone finding out was unbearable; we were so terrified that if people found out they would treat us badly so we kept silent.
28. We eventually told our closest family about Bryan's HIV status but my impression was that they were not quite sure what to do with the information. We were alone with no family or friends close by, there was no one we could trust enough to tell them about our situation. We became very frightened,

isolated, and paranoid. This stigma and discrimination also made us reluctant to share our story with anyone else. It was simply something you could not broadcast without fear of being rejected or worse, harmed. So, we kept Bryan's HIV status secret.

29. Bryan told me *"if I am going to die, I want to die close to friends and family"*, so we made plans to return to Leamington Spa. In November 1985 we moved back to Leamington Spa. It was an unhappy move which we felt was forced upon us. Our hopes and dreams of a life, career and family in Devon were shattered. It was sad that we had to move, and we were forced to move back in with Bryan's parents whilst we looked for a new home.

30. We could have bought another 3-bedroomed semi-detached house in Leamington Spa but fell in love with a detached 2 bed house which was a bit run down, however, we saw the potential straight away. It was called GRO-C
GRO-C It had been the gardener's cottage on the former GRO-C
GRO-C Estate which used to belong to GRO-C
name was on the deeds and, as an Archive Conservator, I quite liked the historical link.

31. We moved in in January 1986. The new house was more money but it was manageable as we both had good jobs and were still physically healthy (despite Bryan's diagnosis). There was a lot of work which needed to be done and for a time it gave us another focus and kept us busy.

32. Bryan returned to the care of the Haemophilia Unit at Coventry Hospital (which was basically a corridor).

33. The return to Warwickshire brought us back into contact with old friends. We felt able to confide in a few of them so they understood what Bryan was going through. It was during this time Bryan's personality changed. He began drinking heavily and generally stopped caring for himself. I was busy with work and trying to do up the house and tried to understand what he was

going through. Although Bryan was physically well, he was not well mentally and being told that he was dying had affected his mental health. He became obsessed with living for the day.

34. In 1986 we split up for a couple of months because of the pressure, it was his decision and I was devastated. Looking back, we were dealing with a horror of enormous magnitude in a hostile environment when attitudes to HIV/AIDS were appalling. The stigma and discrimination we continued to see was terrible. We saw how others who were HIV were being ostracised by neighbours, family, employers – people were losing their jobs. We heard stories of homes being daubed with graffiti. We were hearing stories about discrimination within the Haemophilia community, for example children with HIV were not welcome and were not allowed to mix with other haemophilia families, not infected with HIV. It was relentless.

35. When we got back together we had a long and heartfelt discussion about what we wanted from life. All we wanted was to have a normal life, which included having children. We sought advice from Coventry Hospital in 1986 and told the doctors that we would like to have children. We were told by Dr Shinton at the Haemophilia Centre that *"it is not a good idea but if you want to go ahead, we will monitor you"*. At the time, I had not realised that testing me for HIV and "monitoring" might not be in my interests. I believe that they were waiting for me to become HIV positive.

36. We were offered no advice – we were just "monitored" – looking back, and with the other evidence unfolding, it makes me shudder. We went to doctors because we needed help and support. As we went ahead they tested me for HIV every month, there was nothing regarding reducing risk of infection, ovulation or pregnancy.

37. In 1987 as I found out I had tested inconclusive for HIV, and was waiting for confirmation, I decided to apply for a job at the Shakespeare Trust, in Stratford upon Avon. Dr Levi Fox, the Director at the Trust, wanted to

interview me before I went on a last-minute holiday to America. I got the job but was not aware of that until I returned from the States: he told me that he was told by a former boss that I was the best in the country for the post.

38. So, within a few short weeks after I found out that I was HIV positive, I got a new exciting job and been on an unplanned holiday which took in personal tours of the Getty Conservation Studios (due to my professional links). That greatly inspired me as an archive conservator and distracted me from the gravity of my HIV status and to distract myself from the loss of ever having the family I expected to have when I married four years earlier, I threw myself into the new job as the first ever Archive Conservator at the Shakespeare Birthplace Trust in Stratford upon Avon. I designed and oversaw the establishment of a new conservation studio. It kept me busy and distracted. Looking back, it was probably my substitute for a baby.
39. I loved my work; it was to be somewhere I would spend the next 12 years of my life, taking pride in my profession and achievements caring for some of the most important archive and library collections of international historical significance including the conservation of Shakespeare's First Folio (1623) for which I was be praised by a Shakespeare academic who was a renowned expert on the First Folio.
40. During those years I nursed Bryan as he became seriously ill and eventually died of AIDS. On top of watching my husband die I felt like I'd lost everything, my hopes my dreams and, there was the stigma and discrimination of HIV/AIDS.
41. I felt overwhelmed. The effect of contaminated blood has impacted my whole adult life. It killed my husband at the age of 34, I was a normal healthy young woman with all my life ahead of me when I met Bryan. It prevented me from having a normal healthy life and denied me the opportunity to have children and a loving family life. It destroyed the career I loved. It has impacted on family; my mother, my brothers and sisters. They have witnessed me suffering, my elderly mother cared for me when my health

deteriorated, they saw how I was subjected to unfathomable cruelty by the very organisation set up to support my husband and I – the Macfarlane Trust (MFT).

42. Watching Bryan dying in front of me years before, his body becoming emaciated and not being able to comfort his severe pain is ingrained on me that is difficult to describe in words. I tried my very best to give him the love and care he needed in his last few years. Looking back, I do not know how I coped. When Bryan was dying, we stood in the kitchen and hugged. He was fraught and said to me he was worried about what would happen to me after he died. I tried to comfort him and told him I would be okay – he died a week later – I realised after that I was giving him permission to die.

43. A part of me shut down watching Bryan die whilst dealing with a hostile world that discriminated and stigmatised those of us who were HIV. Being HIV positive in a harsh world full of fear and cruelty, the 1980s/90s was a terrible time to be diagnosed with HIV/AIDS. I do not think I have ever recovered. Because of the 'charge' on my home and years of battling MFT, I cannot begin my own recovery as I am constantly reminded of the past and the final years of Bryan's life. I suffer from chronic traumatic stress and I often break down in a state of being completely overwhelmed. The way the staff and trustees of MFT have treated me has not allowed me to grieve properly. Being shackled to this Trust by way of a charge on my home that should never have been placed has been an unending battle for three decades on top of living with HIV and everything else I have lost. I just cannot understand the cruelty - not just back in the early days, but right up to when the trustees were winding down towards closure, they showed no compassion. Dumping, as I see it, the loans and charges on THT and sending us a letter a week before Christmas 2018 to tell us to contact THT as the 'charge' on my home had been transferred to THT was an act of wickedness I cannot comprehend. The fact that THT has not acted swiftly to alleviate the distress has compounded the suffering. As if I had not suffered enough. I long for the gentle shy woman I was when Bryan and I started out

in life together all those years ago. I wonder where we might be had this never happened.

Section 6. Treatment/Care/Support

44. In September 1989 Bryan found a lump on his neck. I cannot remember him being ill but he had a biopsy on the lump which turned out to be non-Hodgkin's lymphoma. Prior to the operation they boosted his Factor VIII levels with blood products but he was not given any Factor VIII post procedure and when I visited him in the hospital he told me that he had to fetch it and inject it himself. This was one of the many times we experienced fear and discrimination within the medical profession because of our HIV status.
45. At some point in or around 1990 Bryan changed his Haemophilia Centre from Coventry to Oxford. The decision was made based on breakdown in trust in Dr Shinton and Coventry Unit. We were impressed with the support and treatment we both received at Oxford Haemophilia Centre (based at the Churchill Hospital) in contrast to that we had received at Coventry. I wished he had moved years earlier.
46. Although Bryan had undergone radiotherapy he was not expected to live. True to his spirit he fought on with every intention to live whatever life he had left. In 1991 Bryan brought a Land Rover, had it kitted out professionally as a camper, I sewed the curtains and made cushions, and he drove all the way to Iceland, via ferries from Scotland taking in various islands on the way including the Orkneys, Shetland and Faroe islands. The trip took him 5 weeks and he drove everywhere. I could only join him for part of the trip as I could only take 2 weeks off work. I met him in Iceland and we drove around there.
47. I made a small leather bound book for him to take on the trip as a log book and he also recorded his thoughts into a cassette tape recorder. We had a

wonderful time I still have the log book and tapes in a box. He came back from Iceland in the late summer of 1991 and that was pretty much the beginning of the end for him. He underwent more tests including surgery and chemotherapy. But the cancer had gone too far.

48. Prior to the cancer developing Bryan was taking AZT in enormous doses to control the HIV, which was the prescribed norm at that time. He always said that he did not like taking it as it made him feel worse. After they identified the lump in his neck he underwent radiotherapy which stopped the beard growth on one side of his face so he had to shave after that and could no longer grow a beard.
49. Whilst the social worker and the nurses at Oxford Haemophilia Centre were kind to us, no counselling or psychological support was ever made available to Bryan or me despite being infected by the NHS.
50. Bryan died on 13 March 1993. I became very scared to even imagine what would happen to me when my health deteriorated.
51. Some years after his death I did the best I could to stay healthy. I focussed on my professional life as an archive conservator and returned to The Shakespeare Birthplace Trust. As a mid-career development, I was accepted on the Royal College of Art/V&A Conservation Masters Programme where I studied for an MA in The Conservation and Collections Care of Paper Based Objects at the Theatre Museum. I spent my time between the Paper Conservation studio at the V&A, the Theatre Museum at the time based in Covent Garden, and Blythe House in Olympia. I loved it. I felt alive and privileged to have such a wonderful opportunity. No one knew of my HIV status.
52. As part of my international development it was suggested I go to The Humanities Institute in Austin, Texas – which would have been very difficult at the time given the restriction on entry for people living with HIV (ironic given the source of infection). I could not tell anyone of my HIV status so this

caused me further disappointment that the aspirations I had, and the opportunities open to me, were being denied. My life began to fall apart; I was falling ill but due to the nature of my condition and the stigma and discrimination surrounding HIV I still felt that I could not tell anyone about my health. After some time, I confided with my course director and my tutor and they told me that they had thought that I had anorexia.

53. I needed time out and to be able to come back to my studies when I was feeling better. So, I took a year out. It was to be a life changing year as I almost died. I was under the care of the Royal Free Hospital and Professor Margaret Johnson told me that I was dying. I had AIDS, and that I had both pneumonia and CMV in the brain. I was fortunate that the CMV did not go to my eyes as it could have left me blind. I began treatment and I spent a period of time recuperating in Mildmay AIDS Hospital in East London. It was a frightening experience. I had to start taking anti-retroviral medications, which was something I had been desperately trying to avoid.

54. The whole treatment was vile. I hated taking medications after seeing what they did to Bryan. I found despite being on an AIDS ward in the Royal Free that stigma and discrimination still existed, that as a woman assumptions were made that I contracted HIV through drug use. On a later hospital admission, I was shouted out by one of the nurses which was a very low point for me. I told my consultant that I was only willing to agree to medication at the last moment, when it was absolutely necessary but Professor Johnson told me that this was the last moment.

55. As I started to get stronger, I decided to finish my postgraduate degree. On returning to my studies I felt better in myself – having something to strive for was very important to me. Unfortunately, I soon became ill again and instead of resting I began to stress about deadlines for the MA. The deadlines were extended, but this did not help. I kept getting more work and having to move more deadlines. I felt progressively worse and eventually I ended up back in hospital. Whilst recovering, I received a letter from the Royal College of Art stating that following a meeting of the ABCD Board they decided that my

place on the course was terminated because I could not meet the deadlines. I was devastated.

56. At the time, I accepted the decision of RCA because I was just so exhausted and concentrating on getting my health back. I contacted the UK Coalition for People Living with AIDS for support on rebuilding my life. They were brilliant: one of the advisors working for the coalition assigned to support me began to discuss with me what I would like to do to rebuild my life. The advisor listened very carefully to me and realised that I had a problem with the way I had been ejected from the Royal College of Art/V&A course. He advised me that it was discriminatory and unfair given I was ill and in hospital at the time. He told me the UK Coalition could help and we could appeal. I felt such gratitude to this man who I had only just met because he listened and cared, he saw how I had been treated and wanted to help. It is times like that when complete strangers show compassion that has kept me going at times.

57. Whilst I was able to access support within the HIV sector, during my time as a volunteer and briefly as paid worker in the sector, I did not come across others from within the haemophilia community. Nor were we seen as a specific group in need unlike other specific groups i.e. gay, drug users, sex workers. I was briefly a Trustee (vice-chair) of Positively Women (now Positively UK) and I worked briefly as Liaison Officer in 1999/2000 based in Crouch End, London for Positive Futures; a Pan London Consortium of HIV organisations. I worked with all the main HIV organisations at the time; THT, Body Positive, London Lighthouse, Globe, Positively Women, FACTS, Blackliners, Elton John AIDS Foundation. It was through my experience during this time that I realised that other people who were also HIV had been able to access some excellent services and support which was very well funded but was not available to those in the haemophilia community - certainly not to those living outside London.

58. I appealed to the academic board on the decision to terminate my course and with the help of the Student Union I went to the board meeting to put my case. Sir Professor Christopher Frayling was the Rector who chaired the board which consisted of professors and Heads of Departments at RCA. Sir Christopher was not at the original meeting which made the decision so I could hear my case for the first time. I argued that the decision was unfair. Sir Christopher asked me what I thought they should have done given my illness. I said that I should not have been given deadline after deadline but given the opportunity to go away and get better. The panel members were very warm and I felt heard.

59. After the meeting, I received a letter accepting my appeal. It was an uplifting letter. I was offered my place back with open-ended invitation to finish my master's degree whenever I was ready. I was so pleased about this. I was also told that the panel all praised me for my courage. I still have that letter. Again, it was a gesture of kindness and humanity towards me. It helped me enormously in the midst of all the horror I was experiencing as I had been so ill. The contrast was so different to what I had come to expect from the Macfarlane Trust (MFT). It is those kind acts of humanity that made me break down in tears as it pierced the armour I'd had to develop to survive. It was painful but also helped me to keep going.

Section 7. Financial Assistance

60. Somehow, probably through the Haemophilia Centre in Coventry or the Haemophilia Society, we found out that some financial assistance was available. Like most Haemophiliacs at the time, Bryan and his family were members of the Haemophilia Society. As a part of their membership they would receive circulars, so it is possible we found out about the financial assistance that way. The Macfarlane Trust (MFT) was set up in or about 1988 to provide financial assistance to haemophiliacs, and their families, who had been infected with HIV.

61. We applied to the MFT shortly after it was set up as money was tight and we'd had to buy storage heaters to keep warm so debts began to rise. Keeping warm was essential to staying well. I have a letter sent by Bryan responding to a letter from the Trust which stated that there was no more support available to us unless we agreed to undergo debt counselling. Bryan tried to explain to them that we did not have a debt 'problem' and the only reason why we were in this situation was our HIV diagnosis but they would not listen.

62. I remember calling a social worker at the MFT called GRO-D in desperation because we needed some financial support. GRO-D told me over the phone after it was agreed to give a small grant that "*there ain't no more where this was coming from*". I still recall the pain taking that call. I could not understand how they treated us. We did manage to get some money for essentials such as a cooker, but the whole application procedure was a very painful experience and degrading.

63. The process of applying for grants for assistance was always very difficult. If you wanted the MFT to pay for some essential services for example, plumbing or heating you had to provide them with three quotes before they would even consider the application. It was very embarrassing. There were constant delays and, no matter how urgent the matter was, we were often told to wait until they had a trustee meeting and to just sit quiet until then. Personally, what always bothered me the most was how they spoke to us. They seemed to forget they were dealing with desperate and dying people.

64. As stated above, in 1989 Bryan's health started to decline. Bryan was diagnosed with Non-Hodgkin's Lymphoma in September 1989 which, at the time, was incurable and related to his HIV. When it was suggested he have radiotherapy and we knew that Bryan would have to give up work altogether. I was devastated and rang John Williams, the Administrator at the MFT, from the phone box at the hospital. I have a strong memory of being very upset and pleading for help as I was worried for Bryan and asked if they

could help him so that he did not have to return to work. At the time Bryan was being paid his salary through sick leave but this would dry up within weeks and, I asked for financial support from the MFT to cover our basic household monthly expenses.

65. Mr Williams's manner was very matter of fact and lacking any sympathy but he assured me that he would be in touch again. After Bryan came out of hospital we had a long wait but eventually Mr Williams said he would visit us which he finally did over two months later in November 1989.

66. Bryan and I had been stressed out in the intervening months worrying about the mounting bills and the fact that Bryan could not work. I remember that it was late at night and it was dark outside when Mr Williams arrived. I think he had commuted from GRO-C which I believe is where he lived. We had a big living room, I remember very clearly because when Mr Williams walked in to the house he said "*hmm rather large isn't it*" and his eyes went around the room and up. At the time, I thought 'what is he was trying to say?'. That our house was rather large, as if we should not have a nice house?

67. Mr Williams said to us "*this is the only way we can help you, we can take the mortgage off you and make an equity loan*". I understood the idea. But we were basically told "*Take it or leave it*", there was no other choice. What we wanted was a grant which is what the MFT had been set up to do and they could have supported us with grants to cover the monthly income we had lost because of Bryan's failing health. They had given grants to us in the past. We did not need them to pay off our mortgage, just to grant us extra money so that we could meet our monthly outgoings. Our biggest fear was that the house would be taken away from us but that did not mean we needed the MFT to invest in our house, which is what an equity charge was. There was no negotiation. They knew that we could not go to the Coventry Building Society and say "*sorry we cannot make a payment because my husband is dying of AIDS*".

68. I do not think Mr Williams was used to anyone questioning him or MFT support (or lack of it). We had no choice but agree to this loan. We went through the application process and the MFT still uses this as evidence that we wanted a loan, and that we approached them *for a loan* which is not the truth at all. We were forced to make the application because there was no other option, Bryan was dying and we had very little money coming in. The MFT put a man who was dying of AIDS, (he had been told he had only 18 months to live) under extreme duress to sign over our home to keep a roof over our heads – when other options could have been made available but MFT chose not to offer other options.

69. Despite Mr Williams knowing that Bryan was very ill and we were worried about paying our bills the application process was delayed, so we were in a situation where not only were we being forced to accept what was on offer but that offer was very slow in coming. We were becoming more and more stressed by Bryan's health and our financial situation. I had to contact the MFT to see what the delay was and I wrote letters chasing them. I was polite, because that was how I was raised and I asked about the progress of the application.

70. The equity loan was eventually finalised in June 1990 nine harrowing months after my initial approach for financial support. The equity loan was not what we wanted or needed. We needed support to help cover monthly income lost by Bryan having to give up work. He was dying and what we needed were grants to cover that period of time.

71. Before Bryan was diagnosed with HIV he used to regularly go to a home gym of one of his friends. Following his diagnosis and when he started to become ill, he believed that keeping fit would help him to stay healthier for longer. He contacted the MFT and asked for a grant for a small home gym kit to keep in the house. It was a few hundred pounds, a multi gym that could be erected in a spare room. This would allow him to build up his strength without the embarrassment of attending a public gym with his puny body and would have allowed him to manage his bleeds. He told them he wanted to

keep fit. His application was declined on the basis that *"this would not be good for his Haemophilia"*. I remember that after receiving that letter Bryan was in tears. It was one of the rare occasions when I saw him cry and he told me that he felt that his autonomy was being taken away.

72. I remember that even seeking help for essentials such as respite care was met with lengthy forms and delay. To get approved, all applications had to be presented to the trustees for them to make a final decision. If you ever dared to contact them and ask about the process of your application, you were met with rudeness from the staff and made to feel that you were begging for money.

73. The application process often required a letter in support from medical professionals and HIV consultants. Even for the most basic stuff. There was no privacy. Bryan did not get access to assistance from social workers until we moved to the Oxford Haemophilia Centre. Applications had to be supported by evidence from medical consultants. Even with social worker assistance the application process was difficult to navigate. I was told at Oxford Haemophilia Centre that the trustees and staff at the MFT had social workers and nurses in tears when they tried to apply for support for beneficiaries. Professor Johnson had to confirm that I needed basics like a bed. It was ridiculous and a waste of doctor's time. Unfortunately, this continues to this day with the new scheme EIBSS. There is also a worrying lack of knowledge of HIV with the new Scheme. GRO-D who is a senior member of staff told me in a Focus Meeting in November 2018, when challenged, that she obtained her information on HIV from the internet.

74. I think the overall management of the MFT was abysmal and for some of us they were very cruel. The MFT was established to help the beneficiaries who were getting into financial difficulties and falling behind with their mortgages as they struggled to keep a roof over their heads as a result of their infection with HIV. I just do not think that enough was being done. We found out that the MFT had £7,000,000 in reserves at one point while denying beneficiaries grants and instead making them take out loans. Beneficiaries challenged

MFT in Partnership Group meetings but were ignored. Attending these meetings and talking amongst ourselves we discovered the inconsistencies and inequitable decisions being made.

75. As recently as late 2018 the MFT was still hoarding money as they were closing down and chose not to distribute it in a charitable way but to transfer it to the Terrence Higgins Trust (THT). THT has now taken on the 'loans' and 'charges' of several beneficiaries. I discovered that The Terrence Higgins Trust is now named as 'Lender' with a charge on my property registered with Land Registry. THT did not inform me. I have asked for a meeting to discuss this. I currently have concerns regarding the transfer of 'loans' and assets of MFT to THT and it is causing me distress.

76. Ian Green CEO at THT seemed helpful at first but currently appears to be delaying sorting out the issue of the contentious loans. He told me he had been in discussions with the MFT since August 2018 and that during that time he was made aware of the 'two or three' contentious issues around the 'loans' and 'charges'. So, he was aware and has had time to anticipate and plan for beneficiaries contacting him. Recently, it appears that he has stalled and cannot, it seems, find time to meet. He is now saying that there is a 'process' to review which will be discussed at a Trustees Meeting later in March 2019. After initial warmth and assurances in December 2018, asking us to be patient, all was in hand, now a sea change appears to be a siege mentality that causes further anguish. I was left frightened by some of what Ian Green said to me in the two conversations I had with him - one on 17 December 2018 and one on 8 February 2019. For instance, he told me I was lucky the charge had not been transferred to a private company.

77. THT has been slow to react to MFT beneficiaries' concerns - yet not so slow to bank the 'assets' and residual funds. We should be allowed to live and not have these concerns hanging over us. By taking on the 'assets' and 'loans' THT is now involved and should uphold best practice in its duty of care towards us as a community that it promised.

- 75 In 1990 an ex gratia payment of £20,000 was given to haemophiliacs with HIV. I do not know why I did not receive the original £20,000. Years later CEO Martin Harvey said it was only given to haemophiliacs. Very recently I discovered this was not true as Eileen Trust beneficiaries (blood transfusion recipients) received the £20,000. We were lied to.
- 76 As a result of the 1991 HIV litigation settlement Bryan was awarded £32,000 on the grounds that he was married but without children. Those who had children received double what he was given. It felt like an insult and unfair discrimination because the only reason that we had not been able to have children was due to our HIV positive status.
- 77 I found out about my own eligibility for MFT payments from the Haemophilia Society. In 1991, when Bryan received his second payment, I was told that I was also entitled to an award from the settlement money. Under the settlement I was classed as a single person despite being married. I received a total £23,500. I did not question this amount at the time. Now looking back, I do not understand why they chose to classify infected partners as "single". I can only assume this was a money-saving exercise. I think their decisions were illogical and disrespectful.
- 78 Sometime after Bryan's death, I contacted the MFT and asked for help as I wanted to move house. However, they kept saying that I needed to pay back the amount that we had 'borrowed'. I contacted a lawyer in Stratford upon Avon and asked him to help me but he was unsuccessful. I have a copy of a letter that John Williams sent to the trustees in which he said that *"this is about the fifth go-stop on sale since her husband died....."* If *"not taken up by February deadline, our future policy should definitely be "the contract – no more, no less"...."* I was not in a position to move as I had no money and no support or understanding from MFT. I also felt the situation I was in was

of their making. It is an indication of the contempt Mr Williams held for a HIV infected woman who had been recently widowed.

79 When John Williams wrote letters to me (which may be read) he always appeared very nice and polite but when we spoke on the phone it was a very different story. When discussing my request to move and for MFT to sort out the charge on my property he yelled at me "*Mrs Walton, you would be thrown out by your ears if it wasn't for this Trust!*" He was clever enough to know that those conversations were not monitored and his behaviour was not recorded anywhere. I think John Williams was a prime example of how the MFT really treated those they were supposed to help.

80 In the above mentioned internal document, Mr Williams describes me "as a woman who wanted to eat her cake and still have it". I argued about the circumstances of the equity loan. I questioned the legality, the morality of profiting from a dying beneficiary. Grieving for my husband and trying to move on, HIV positive and alone, instead of compassion and understanding, I was treated with brutal contempt because I had the 'audacity' to challenge the MFT.

81 Under other circumstances the house would have come to me as my husband died and we had some mortgage protection on the property. Due to the protection being taken away with the equity loan I lost protection that would have paid out on Bryan's death. It was a mess created by MFT. Instead, with the MFT unwilling to help resolve a situation, I stayed in the house, trapped for years, after my husband died. When Mr Williams left the MFT, and the new chief executive was appointed, I again approached the MFT - unsuccessfully.

82 Around 1998, I made contact with a trustee called Tim from Wales, who was a social worker who he agreed to help me try and untangle the mess. I had a meeting which included trustee Rev Alan Tanner and CEO, Ann Hithersay at Alliance House. I am not sure if this was before the meeting or another time

but I remember clearly being at Alliance House and Ann Hithersay shaking her head and telling me gently not to worry - the charge on my property wouldn't matter. As if it would just magically disappear. What she said made no sense. Unless the charge was taken off by MFT it was still on there and legally binding. I took a friend with me to meeting with trustee Rev Tanner who witnessed what went on and supported me during this meeting. The MFT finally agreed for me to move but the charge would remain and would be applied with profits to a property in London where I found work. Again, I had no choice, I had to accept the transfer of the charge otherwise I would be trapped in Avon Dassett. In 2000 I sold Avon Dassett and purchased a small two bedroomed terrace house in GRO-C London.

83 Seven years after Bryan died, I finally felt able to leave the memories behind in Warwickshire and make a life for myself in London; however, in 2003 I became very ill. I had developed what was known at the time as 'full blown' AIDS.

84 Having experienced my health seriously declining, I needed to be closer to my family. My mother had been my main support. She was by this time in her late 70s, but she cared for me. So, in 2005, I approached the MFT again. They advised me that they were going to meet with me to discuss the matter. This was arranged by MFT's social worker, GRO-D who wrote to say she would come to my house with the then CEO Martin Harvey. At this point I was still recovering and was very weak, so my mother aged 77 at the time was there caring for me. GRO-D did not turn up but unexpectedly and without invitation trustee Pat Spellman arrived instead to accompany Mr Harvey. The discussion was unpleasant and I felt intimidated and unsupported. The 'charge' on my property and arrangements to allow me to return to Warwickshire were discussed. When Harvey and Spellman made their suggestions, my mother was her usual pleasant self but unequipped to help me deal with negotiations – I was left to fend for myself. At one point Harvey and Spellman went out of the house for a discussion in private. I was clearly very ill – I have a photograph taken around this time which shows

how ill I was yet, instead of showing compassion or care, it was a tense meeting where I felt humiliated and taken advantage of and that my elderly mother was also taken advantage of. During that meeting Harvey agreed to write off the equity profit they made from the original charge. But when the papers were drawn up some time later he only took the profit off the profit from the London house and not the profit from Avon Dassett. The meeting should never have taken place without the support I needed. At least I should have had the support of a social worker – I heard afterwards that **GRO-D** left the MFT. Following that meeting a charge was transferred to my current home in Warwickshire. I have since acquired through Subject Access Request a copy of Mr Spellman's report of that meeting to trustees. It is shocking and very unpleasant to read the contempt he held for me.

85 Before the Archer Inquiry MFT regular payments were very little – at the beginning very little which over the years increased but still only to a few hundred pounds a month.

86 After the Archer Inquiry the monthly payments increased. For the first time I had a small income. The payments did not in any way make up for the financial decline and loss of earnings as a result of the toll of having lived with HIV for decades.

87 In 2017 the new scheme EIBSS was set up and I was given slightly higher payments. These are not guaranteed and will be up for review. Which leaves me with a profound sense of insecurity. The government had proposed to raise the payments further for those with mono HIV or mono Hep C stage 2 in 2018 but that was withdrawn because funds were going to go to payments to those raised from Hep C stage 1 to stage 2 instead. It had the community split and caused outrage as they were seen to be robbing 'Peter to pay Paul'.

- 88 I continued to get my discretionary top up from the old scheme of £360 per month. As eligibility for those payments is based on the household income I will never live with anyone. I feel that I should be able to be independent and anyone I should happen to live with should not have the intrusion into their finances. I feel that in a way, because of this policy, the Trusts and now the EIBSS is controlling people's lives and preventing them from moving on.
- 89 It is especially difficult for me because I am both a primary and secondary beneficiary so my situation is a bit different to that of non-infected widows. I tried to put that across to the MFT when they were in charge of making the payments but they told me that this goes against their policy. They told me that the policy states that you "cannot be both a primary beneficiary and bereaved".
- 90 When EIBSS came into force, I made a complaint and challenged the policy. I asked for a copy of the policy. It did not exist. It never had. EIBSS admitted it had taken it from MFT by word of mouth. After complaining, EIBSS agreed to classify me as both primary and bereaved partner, I was able to claim either the primary or bereaved partner top up – whichever is greatest. This allowed me to be awarded a further top up of £5,000. Again, there was no back payment available for the years I missed under the MFT. I was denied payments of thousands of pounds over the years that had been given to uninfected widows.
- 91 When I look at the way widows are considered for discretionary payments compared to infected beneficiaries there are two separate complicated and confusing systems, there is no logic to how they devised the scheme. With other discretionary support, it is huge effort to understand and the procedure is complicated, the staff lack knowledge, often they conflict each other and backtrack on what they told us. I just do not think this is right, we were put this situation by the government. We should not have to beg or chase that money. Sometimes I think that the EIBSS (and in the past the MFT) took advantage of the fact that some of us were too sick to fight for the money which we were entitled to claim.

- 92 Although it feels like EIBSS are more accountable so that when you bring a complaint forward you can expect something to happen, in reality the outcome is the same. People seem to be nicer and there is not the rudeness that there was under the MFT, however, those are only superficial problems. The big issues remain. I am under the impression that now people are made to jump through more hoops to get the payments and criteria has become stricter. For example, I think they are more particular about the wording on applications, and continue to reject applications if they are not satisfied with the information provided despite supporting letter from GP's.
- 93 I am also worried that the new scheme is unfairly tailored towards Hepatitis C infections. As according to their own statistics they are only dealing with 64 mono HIV cases, approximately 230 co-infected as against over 2,300 Hepatitis C cases. Their understanding of HIV and especially living with HIV for decades (since the 1980s) is very poor. The case workers are not trained well enough to deal with people like myself. Their approach to HIV is based on assumptions not backed up by evidence. For example, EIBSS is now only offering funeral plans for those infected with Hepatitis C but not HIV. When I asked the reason for this policy, I was told that "*HIV is a manageable condition*". I was absolutely horrified when I heard that coming from someone who works for the scheme. When I challenged and asked for the medical evidence for the policy, [GRO-D] told me they got the information off the internet.
- 94 It is wrong to compare newly diagnosed HIV infections, that may be more manageable, with those that are living with HIV infection for decades. For example, we have been significantly damaged by long term physical and mental effects of HIV and the medication prescribed to treat it. Many young people do not understand the impact of HIV in the 1980s, the mental health issues and the experimental and toxic drugs people have had to take. HIV is not curable and is only kept under control by medication which has to be

taken for life. It is accepted that AZT in high doses in the early days was not a wonder drug and is likely to have contributed to people's death or health problems today.

95 It makes me so cross that we all received those infections directly or indirectly from the NHS treatment and now they make us jump through hoops for even minimal financial assistance.

Section 7: Financial Assistance

Impact of the Trusts

96 The trusts, and in particular the way in which the MFT dealt with me, has had a massive impact on my life. I had to deal with Bryan dying and living with HIV. Those things happened to me and I had to accept it. How it happened will hopefully come to light as a part of this Inquiry's investigations. However, the important thing for me is how I have been treated by the Trusts and what hurts the most is the fact that they were set up to help people living with HIV. I think that one of the main reasons for those problems is that the MFT was set up and solely funded by the Department of Health, it appointed Department of Health trustees and Haemophilia Society appointed trustees. This close relationship caused a lot of problems in keeping the MFT accountable to its beneficiaries.

97 In 2006 I, once again, voiced my concerns about the way MFT operated to Martin Harvey CEO of the MFT. Shortly afterwards the Chair of MFT, Peter Stevens wrote me a letter the content of which was beyond anything I could imagine. In that letter he implied that I was ungrateful and that I ought to think of others; that I do not have children nor was I a haemophiliac or had Hep C. He might as well have stuck a knife in my stomach. I was extremely ill and was recovering from a set-back in my health. I had recently come out of hospital. I could not imagine anyone, not even he could write those things

but this is just one example of how powerful, uncaring and the fact he put it in writing showed to me how just how arrogant he was.

- 98 I think that further difficulties arise from the fact that people in positions of power within the MFT and EIBSS have no understanding of how it feels to be infected with HIV even though some of the trustees appointed came from the infected community.
- 99 In addition to the Department of Health there was also a lot of overlap with the Haemophilia Society, and some were trustees of both at the same time. I believe this also stops the Haemophilia Society from being independent. I tried to make the Haemophilia Society see what damage the MFT was doing to its beneficiaries but those two organisations are too intertwined and a former Chair [GRO-D] and the current CEO Liz Carroll made excuses and I felt fobbed off. A few years ago, I asked Liz Carroll to help me with the problems I was having with MFT. I asked if she could seek help from [GRO-D] [GRO-D] who is one of the Haemophilia Society Trustees (HS) who had been appointed as a trustee on MFT Board by HS. She wrote to him asking him if he would help and asked him to contact me. He never contacted me.
- 100 From my own experience with the former chief executives and the trustees of MFT it was clear to me that there was a hierarchy of decision making, and not all trustees had the same power or influence but equally no one wanted to take responsibility. I, myself many years ago was a trustee of Positively Women based in Islington – now Positively UK. Before I started I was sent to for training to a Volunteer Centre in Islington which covered duties and responsibilities of being a trustee. I do not know what, if any, training the trustees for the MFT had but from my experience they are breaking every rule in the book.
- 101 After I received the devastating letter from Chair Peter Stevens I asked Martin Harvey CEO at the MFT about the complaints procedure, as I wanted

to put one forward, I was told there was no complaints procedure because nobody complained. I insisted that I wanted the whole board to know what was going on but I was told that only 'senior' trustees would deal with it. Peter Stevens stepped down as Chair and it was a year before the new Chair Christopher Fitzgerald finally dealt with it and issued an apology and agreed that the letter should never have been written.

102 I regularly attended Partnership Meetings with MFT which at first seemed to be useful as I saw this as an opportunity to voice some of the concerns we had with the MFT. It also gave us an opportunity for beneficiaries to meet up. There seemed to be progress but the meetings ceased after the Archer Inquiry. They were resurrected when a new CEO Jan Barlow and Chair [GRO-D] were in post. Unfortunately, this did not last long as the meetings deteriorated to the point that we, beneficiaries decided to stop them as there was no point – we could not agree with [GRO-D] on the Minutes as a true record of what went on.

103 At one Partnership Group meeting in May 2013 I was verbally abused by CEO Jan Barlow. I was bullied in front of everyone. I was devastated. After the meeting, I spoke to another beneficiary who was supposed to be chairing the meeting who told me that he thought it was just "banter". But it was not innocent or funny it was just another example of the culture of bullying by the MFT. I do wonder if some of the younger beneficiaries who grew up with the Haemophilia Society and the MFT were groomed into the "charitable" ways of the Trust. It seemed if your face fitted you were looked after. However, if you dared to question their ways you were considered trouble. There were often breaches of confidentiality, through trustees and staff, who would talk about what other beneficiaries were getting in grants and support. My friend who witnessed the attack on me by Jan Barlow advised me to write it all down as soon as I could so I would have some evidence of what was said. I passed my note of the abuse onto my MP. At the time, I did not think much about it, I just wanted my MP to know what was going on but he took it upon himself to raise this issue and pass the

note to the Minister. I received a standard response from the Minister, who replied saying "*I am sorry to hear that but trusts are independent*". I tried to let people know what the Trusts did and how they treated us but it felt that no one wanted to listen and still do not want to acknowledge it.

104 Some of the MFT's trustees, such as Allister Murray, Matt Gregory and Jamie O'Hara are relatively young. They would have been children when the infections due to contaminated blood first became known. So, I don't know how they can understand what those of us who were adults in the 1980s went through. Any of the trustees who are HIV infected themselves but children or babies in the 1980s, could not possibly be aware of the reality of living in those early days within the context of AIDS in the 1980s and difficulties of being an HIV positive adult at that time. It was toxic; Bryan and I were under extreme duress. I believe this lack of understanding or willingness to understand, or the lack of compassion fed into the way the MFT trustees handled the historic injustice such as the loans and charges placed on beneficiaries' homes. We could not be open about our HIV status. We lived in danger of being attacked, people were losing their jobs, we were isolated and shunned by society. It was a terrible time to be diagnosed. The MFT was the organisation set up to help us, the only source of information and support open to us. Unlike normal people, we could not go to a bank or other financial institutions, anyone in fact, to discuss money or difficulties as we would have to explain the fact we were HIV positive. Everything was quite simply extremely difficult for us adults dealing with this at the time.

105 When I first approached my MP Nadhim Zahawi. I wanted to talk to someone about the MFT and my problems regarding the charge over my home. The only thing I hoped to achieve was to start a dialogue between my MP and the MFT. I told Mr Zahawi that I wanted to move home and I could not understand why the MFT would not help me from doing so. It was my MP who told me that the charge should be removed all together. He was

astonished by what had happened and wanted to help me. However, my relationship with the MFT went from bad to worse when Mr Zahawi made a speech in a Westminster Hall debate at the House of Commons in October 2013 and said that MFT was 'unfit for purpose'. Three weeks later in a board meeting the MFT made a decision and made it official that they would not support a move and I had to pay the charge if I sold my house. I believe this was a vindictive decision. Roger Evans told Mr Zahawi it was a unanimous decision yet, Alan Burgess, a trustee said he fought for me at that meeting.

106 Mark Simmons, a Social Worker at Birmingham Haemophilia Centre MFT, tried to support me. Mr Simmons, had extensive experience of dealing with the MFT. He applied for grants and supported many who needed help. Before Mr Simmons retired he wrote to my MP Nadhim Zahawi on 15 February 2015 and said *"Historically the MFT would allow debts/loans to be cancelled upon the death of the Primary Beneficiary, or it would be made clear repayment would not be sort. Over the years I have negotiated with many financial institutions to right off or greatly reduce individual's debts on health grounds and inability to pay the full amount back. The MFT will no longer discuss, never mind negotiate or right off loans/debts. Individuals have had grants far surpassing the level of your constituents debt. I received several grants for a PB (Primary Beneficiary) in one year, one application was for £30,000, in all the grants exceeded £55,000. I do believe your constitute should have been offered grants, and the loans should not have been interest linked. Sadly the MFT's loan system was not set with in an equitable framework, it was a matter if your face fits or if you were seen as deserving."*

107 After dealing with the MFT for the last three decades I recently became familiar with the term *"gaslighting"* [Which means persistent manipulation which causes someone to doubt themselves in society.] Because of the nature of Haemophilia and the demographic of those infected it is an extremely male dominated community. As a woman and not a haemophiliac I think I was looked down on, bullied and told that I was over sensitive. In the

first letter sent by the MFT to Mr Zahawi the then Chair **GRO-D** advised him not to bother with me and implied I was trouble and not worth dealing with. Fortunately, Mr Zahawi disagreed and told **GRO-D** so. Over the years, I applied to the MFT for information about me under the Data Protection Act and I saw the terrible things they wrote about me. My MP wrote many letters to the MFT including suggesting a face to face meeting but for five years they refused to meet him. They refused to meet a Member of Parliament representing his constituent and refused to communicate further.

108 In relation to the charge on my property I cannot remove it. I have tried many avenues including legal proceedings, I spent £4500 with a local solicitor, Lodders and realised that I was in a losing position from the beginning as the MFT had more money than I did and could afford to prolong the argument and bully me into submission. I even suggested professional mediation and approached a mediator Suzanne Lowe from Talk Meditation. She wrote to the MFT to arrange a meeting but the trustees refused to mediate.

109 The MFT's position suddenly changed in February 2018 and the current Chair of the MFT Alasdair Murray finally agreed to meet with Mr Zahawi. The meeting took place on 2 May 2018. Both Mr Zahawi and I expected to be able to engage in a conversation with him and to form some kind of dialogue but I was devastated when the meeting finished after just 30 or 40 minutes with no meaningful dialogue. The Chair just recited several clearly rehearsed reasons as to why the charge could not be removed from my property, for example, that was only fair for me to pay it back because other people have. The only positive outcome was that the Chair promised to look at the charge in the light of the new information that Mr Zahawi was prepared to write to him with and Mr Murray would discuss with the board. I had evidence in previously mentioned internal document that stated that the loans register had been lost in a handover between CEOs. So MFT had for years been unaware of who it had lent money to – notwithstanding the

morality and duress beneficiaries may have been under to take out loans, there was nothing fair about who paid loans back.

110 This MFT board meeting took place in July 2018 but Mr Zahawi did not receive a reply until September 2018. Mr Murray said a thorough investigation had taken place and that my husband and I knew what we were doing and must pay back the loan. Despite being the only witness to events surrounding the loans, I was not allowed to attend this investigation or give any evidence. I was informed that my request for the charge to be removed was refused on the grounds that Bryan and I allegedly approached the MFT for a loan and explicitly agreed to the terms of it, it seemed to me that the board cherry picked the evidence and dismissed everything that happened before. They ignored the fact that we originally approached the MFT for a grant to help with monthly outgoings and were told that the only way to obtain any help was to agree to the charge. Once again the MFT attempted to re-write its history. I was told that, the MFT was due to close, the outstanding debts have been transferred to the THT. [Those debts should have been transferred into grants. They have the power to do that].

111 The trustees talk about fairness but after the MFT underwent an audit in 2004/5 it was stated in a report that the list of unpaid loans had been lost in the transfer from one chief executive to another.

112 Under the Data Protection Act I obtained a copy of a letter written by John Williams, the administrator to the MFT to the board saying *"1. There are two people whose health is at risk, and the double stress factor with the husband's deteriorating health. 2. The Trust is likely to regain capital in shorter term than most (there are no children) and even without the ex-gratia payment the owners have well over the 10% minimum of the equity."* I wonder if they were speculating on the property market and made loans with the intention of making a profit. They also abused the fact that we, the beneficiaries, were sick, frightened and had not been given long to live.

113 The reason why I think it is crucial to tell my story now is because the MFT is due to close by the end of February 2019. As the MFT is closing I believe that it will try to cover up what it has done to us and attempt to re-write its history.

114 The most sickening thing is that this has been going on for 30 years. Bryan died 26 years ago and this situation keeps me back in 1989 when the charge originated and prevents me from being able to move on. I want to live my life but every time I need to discuss it I am made to re-live the last years of Bryan's life. The way the MFT has treated me has led me to believe that they have actually forgotten that I am HIV positive and grieving for my husband and the fact that I will never be able to have a family or live a normal life. This fight has lasted for my entire adult life. At this point I am just exhausted.

115 I had a problem with CEO Martin Harvey. I was straight with him about what, in my opinion, the MFT did wrong and this made him hostile towards me. I saw Martin Harvey several years ago. It was some time after the Archer Inquiry. At the time, I had had minimal contact with the MFT for a few years. We were given some extra money following Archer and I felt, for a short period, that I did not have to negotiate with the MFT. The MFT called a meeting for beneficiaries to discuss how to spend the reserves. At the meeting a trustee, Russell Mishcon, suggested a spending plan and interviewing beneficiaries to determine their needs; many disagreed with him and wanted him to resign. In that meeting I said that I agreed with Mr Mishcon and had no objections. After that meeting I chatted with Martin Harvey – it was a friendly exchange– I told him about my life and my hopes after recovering from serious health issues. He seems pleasantly surprised that we were able to chat. Afterwards he spoke with Mark Simmons. Mark told me later that Martin told him that “*the Trust were rotten to Clair*”. I was surprised to hear that Martin had admitted that. I think that during that meeting he saw me in a different light. I was relaxed because for the first

time in a long time I felt a bit of peace partly due to the extra money we got after Archer. That was the last time I saw Martin before he died.

116 I think if I did not have the upbringing, personality and strength I have I could have been pushed by the MFT into committing suicide. I could never actually end my own life but there were times when I was so desperate to escape the nightmare, that I was driven to such despair, that I can understand why people do. The situation felt hopeless especially when other people are making decisions about your life. This desperation is still with me today as the 'charge' is unresolved and now it has been transferred to THT I feel I have to start all over again with another organisation.

117 With regard to the trustees appointed by the Haemophilia Society that have been on the board the last few years, I simply object to having haemophiliacs that were children at the time of the origins of the scandal claiming to represent the Haemophilia community and making decisions about me. They have never sought my opinion. They have not lived through the stigma and fear with adult perspective of AIDS in the context of the 1980s They do not have the personal experience I have and clearly from their involvement in the decision regarding the historical charge on my home and that of other beneficiaries, as board members lack compassion and understanding. They have some responsibility for the adverse impact on my life.

Section 8. Other issues

118 During the Preliminary Hearings, I met Liz Carroll, CEO Haemophilia Society, and she asked me about the difficulties with the MFT. She reassured me that the Haemophilia Society was not involved with the MFT, but I was sceptical as I know the same people are involved in all of the organisations. She confirmed again in an email in November 2018 that neither she, the Chair of the HS nor the Treasurer have been approached by MFT to take on the debts of the Trust when they close.

119 In 1995 I was interviewed by a woman who came to my home in Avon Dassett for a sound recording project. The East London University Project was led by Wendy Rickard which was to be deposited in the British Library (BL). The tapes captured a contemporaneous account of the impact contaminated Factor VIII had on me as a recent HIV infected widow. My real name and address was given for the record but I was known as Mary on the tapes. I asked for the tapes to be marked for release after 50 years. In 2014 I applied for a British Library card to listen to the tapes. I identified myself to the librarian as one of the interviewees and requested the 50 year embargo be lifted. The librarian could not find a record for me or indeed the original tape recordings. Lead Curator Robert Perks at BL who had been involved with the project eventually told me in an email *"My best guess, if you are certain that you carried out an interview for the BL, is that you might have been recorded by someone called Jean Jones, who carried out a few interviews for the series when it first started. As Emily has indicated, Jean [GRO-A] not long after the project began and had to withdraw. I have a memory that we didn't get all the interviews (I can't remember how many) from her which she had been carrying out before she [GRO-A] and we lost contact with her. You'll note that several of her content summaries are also missing. I have heard nothing from her since."* This would have been evidence I could have submitted for my witness statement.

120 I have extensive documentary evidence which I shall make available to the Inquiry should it so require.

Anonymity, disclosure and redaction

121 I do not want to be anonymous.

122 I wish to give oral evidence to the inquiry.

Statement of Truth

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

Signed.. GRO-C

Dated... *22 February 2019*