

Witness Name: GRO-B

Statement No: WITN1291001

Exhibits: WITN1291002-5

Dated: FEBRUARY 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1960. I live at GRO-B West Yorkshire GRO-B with my wife and our 16-year-old daughter.
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

### Section 2. How infected

3. I have severe haemophilia A. My one brother (and only sibling), C, was 9 years older than me. He had haemophilia and I was therefore also identified as having haemophilia from around the time of my birth. However, according to my

medical notes and records, it appears that an official haemophilia diagnosis was not made until I was 4 or 5 years old.

4. I was treated at the Leeds Haemophilia Centre from the mid 1960s, when it was established at the St James University Hospital, initially under the care of Dr Swinburne, Dr Hardy and Dr Bernard and, latterly, Dr McVerry. During my university years I was treated at Sheffield. In or around 1992, I transferred to St Thomas' Hospital under the care of Dr Savidge.
5. I have been treated with a number of Factor VIII (FVIII) products over a long period of time including Cryoprecipitate. Dr Swinburne would playfully refer to our FVIII treatment as 'jungle juice'. "Have you come for your jungle Juice?" She would say. The Centre had a friendly, touchy, feely sort of atmosphere. I had treatment on demand, varying from several times a week, to once a fortnight or every three weeks or so.
6. The development to FVIII home treatment came some time in or around 1974. Our parents were provided with a deep freezer by social services to store the large brown boxes, each containing 20 vials of treatment to mix and self administer. When home treatment first came in we were told to practice by injecting oranges. With the boxes of vials of frozen product came various other boxes containing the other items we needed; water to mix the product with, a box of needles, and so on. The packaging of the boxes was bland. I believe the source of the product at that time to be from the UK.
7. I remember when the treatment started arriving in a different form, probably in the late 1970s. The treatment came in flashy, glossy boxes with brand names to include Armour, Baxter, Hemofil and Factorate. Everything needed for treatment was in just one box, like a TV dinner. We had no idea that the source of the various products was foreign. We were, as need dictated, given some instructions on tweaking how to mix the different brands of product. It was all about reconstitution methodology. No information was given to me, my parents

or my brother beforehand about the risk of being exposed to infection from blood products. We trusted the doctors and it was all about improvement. The message was that things were getting better. The nirvana was that there would be a cure. The new boxes of product and kit were smaller and more convenient, leaving more room in our freezer for my mother to use. My brother and I thought that our lives were getting better, not shorter.

8. I am co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products. I refer to **Exhibit WITN1291002** being a letter attaching the batch numbers of the American FVIII concentrates given to me and C between 1980 and 1989. I also refer to **Exhibit WITN1291003** being an extract from my UKHCDO Patient annual treatment record for that same period of time.
9. We were first made aware of the risk of infection in the early 1980s from a 'tip off' to my mother. My mother took a phone call from someone we knew through the Haemophilia Society for us to watch something of particular interest on TV. It may have been the half hour *World in Action* programme that I believe came out in 1982. The four of us sat down to watch and were still puzzled 20 minutes into the programme as to how it related to us. The programme was all about monkeys in Africa, people becoming ill in Haiti and homosexuals and heroin addicts in New York. After 20 minutes the penny dropped when it was reported that haemophiliacs were 'now falling victims to the mysterious disease'. I remember thinking how strange it was that all the groups of people affected by the disease start with the letter H'. The letter 'H' seemed to hold significance, being the only logical (albeit absurd) connection between us; the heroin addicts, the homosexuals, the Haitians and the haemophiliacs.
10. The programme was a bombshell. I do not remember the ins-and-outs, but I know that we were amongst many others looking to our doctors for answers after it was aired. Dr Swinburne and Dr Hardy's response was to pour cold water on our fears and told us to take no notice. They too appeared to be bewildered by the

reports but they were calm. They dismissed the programme as unscientific, exaggerated, melodramatic and just 'TV' stuff. They seemed to be sincere and the next 18 months or so it was like a game of tennis. We, the haemophiliacs, would go back to the doctors every time there was something in the media, saying "... but look what's going on now!" and they would respond with reassurances. The word 'AIDS' was being used by the media. I was spooked and stopped having treatment for probably what was between six months and a year. That was difficult for me. C continued with treatment.

11. Our parents did not become parents until in their forties. My brother, being 9 years older than me, played a big part in bringing me up. As we were both haemophiliacs, we went to hospital appointments and meetings together. We are referred to in many of my medical notes and records as the GRO-B brothers'. After that TV programme, C and I protected our parents from worry about AIDS by assuring them that the doctors had reassured us. Soon after that, they stopped asking us anything, although, like others who knew we were haemophiliacs, they would look at us for signs of ill health. When we were with our parents, AIDS was like the 'elephant in the room'. It just wasn't talked about. C and I would keep our worries about AIDS to discussions between the two of us. Normal people (outside the high-risk groups) were getting it and news about AIDS was becoming more prevalent in the media. We did not tell anyone new that we were haemophiliacs. C walked with a limp but I was sporty and active and I looked the picture of health.

12. The hospital started testing our blood for HIV/AIDS and words like 'antibodies' were used. In 1984 or 1985, the hospital called us into a meeting with Dr Swinburne. Dr Swinburne told me and C that she had good news for us. She said that AIDS positive antibodies had been detected in our blood. We had been exposed to the virus and were now protected from it and we were immune to the virus. She told us that we were going to be fine, that we were clear of the virus and that we could 'relax'. In telling us that we had nothing to worry about, Dr

Swinburne, had, for the first time, acknowledged that there had indeed been something for haemophiliacs to worry about in the first place. There is no record of this meeting/conversation in my medical records.

13. Sometime later, we were called back and told by Dr Swinburne that the test results had been 'reinterpreted' and that we did have HIV. In telling us, I remember Dr Swinburne referred to the virus as 'HIV' for the first time. A surreal thought occurred to me that there was now a fifth connection with the letter 'H'. I then started taking my FVIII treatment again. There seemed no point in continuing to abstain. There is no record of this meeting/conversation in my medical records.

14. In the summer of 1986 there was a huge meeting held in the Lecture Theatre at St James Hospital. It was packed with well over 100 haemophiliacs and family members attending. We were told that the outcome of having HIV might be fatal or alternatively just a mild case of the flu. It was like a lottery as there was no way of knowing which of the two outcomes would be the result. For those present not yet HIV positive, they were left with the dilemma of whether or not to continue with treatment as the treatment was not heat treated then. Shortly after the meeting and with the relocation of the Haemophilia Centre to a hospital annex across the road, my former medical team disappeared. I never saw them again. Dr McVerry became my new Consultant. As well as being separated from the hospital, the new Centre (one room and corridor) was unfamiliar to me and felt less welcoming.

15. Dr McVerry scheduled a meeting with me in or around 1988 and talked to me in scientific terms about the virus. He said nothing about the possibility of a mild flu as an outcome. To better understand what he was saying, I asked him if HIV was going to be fatal. He said "yes". I asked him what could be done and he bluntly responded with just one word "nothing". I then asked when I might die

and he told me that it would likely be within two years. There was no cure and no treatment. I was then dismissed and he shut the door behind me.

16. I had a very important business meeting to attend straight after the hospital appointment in a prestigious skyscraper building in Leeds. I remember staring out of the window at that meeting. I had no clue afterwards as to what had been discussed or agreed there. I was so distracted. I drove home and talked to my brother. Soon after, he was given the same prognosis by Dr McVerry.

17. I was not provided with adequate information to help me understand and manage the infection. I had previously been given inconsistent/wrong advice about the diagnosis and what it meant for me in terms of prognosis. In terms of risk to others I was at first told the infection was passed on through blood but then it became through sex as well. I remember someone once told me that even my tears were contagious. I thought at the time that 'I can't even cry my way out of this one'.

18. I do not recall specifically being told about my HCV diagnosis. I do not remember a specific discussion about HCV. There is a handwritten note in my medical records that someone (presumably me) was "told about HepC" on 1<sup>st</sup> August 1991. I was not told that I had HCV whilst under the care of the Leeds Haemophilia Centre. My medical notes and records are incomplete but there is a record that I was tested non-A non-B positive as long ago as 2<sup>nd</sup> March 1983.

19. I had no idea that I had HCV until I was referred by the Haemophilia Centre at St Thomas' Hospital to a liver specialist at King's College Hospital very many years later. If HCV had been mentioned to me before, no-one had ever told me how serious it was. When I changed centres, I remember being asked at routine appointments "What is your Hep C status?" to which I would respond "I don't know". They would mention that I needed testing in what seemed to me to be nothing more than an after-thought. They never did to my knowledge. It was not



something they seemed to get around to doing. I was not interested as I did not know what Hep C was. My concern was that of HIV.

### **Section 3. Other Infections**

20. My medical records state that I have been exposed to the Hepatitis B Virus (HBV). I also refer to **Exhibit WITN1291004** being a letter from Dr McVerry dated 14<sup>th</sup> December 1992 advising of the risk of the Hepatitis A Virus (HAV) transmitted in factor concentrates.

21. I still know nothing about my hepatitis A status.

22. After contracting HIV and HCV without being informed of the risk and/or being properly protected by my government, I have become very sceptical when it comes to government advice. I stopped eating beef when I first heard about mad cow disease despite assurances that British beef was safe. I refer to **Exhibit WITN1291005** being a letter I received in September 2004 notifying me that I am at risk of vCJD. The irony is not lost on me (it is also another 'H' – Human-variant CJD').

### **Section 4. Consent**

23. I am sure that I was tested without my knowledge or consent. I would attend at the Centre for a routine check-up and blood would be taken for what I thought to be routine purposes. As detailed in the chronology to this statement I was tested for hepatitis on a number of occasions without being told.

### **Section 5. Impact of the Infection**

24. The physical and psychological effects of being infected with HIV and HCV are immense and they go on and on. I have developed several HIV/HCV related

conditions some of which have been caused and/or been exacerbated by the medication that I have been prescribed to treat the infections. The physical conditions include liver damage, peripheral neuropathy (nerve damage), lipodystrophy and lipoatrophy (redistribution and loss of fat), arthritis, hypertension, carpal tunnel syndrome, acid reflux and I have suffered from numerous opportunistic infections, such as shingles, anaphylactic shock (I have to carry anti-histamines and two emergency epi-pens) and other skin irritations. I regularly experience nausea and faintness and my stomach is regularly upset (I score every single day upon which I don't inadvertently soil myself as a small success).

25. I am in constant pain with my hands and feet. I have arthritis in both ankles and I can barely walk. I have a mobility scooter. I cannot hold or grip things properly and I need an operation for carpal tunnel syndrome in my left wrist. I also have double tennis elbow. I was sent to the specialist pain clinic at St Thomas' Hospital but nothing suggested to me works. My skin and mouth tingle, I experience random electrical impulses in my limbs and my libido is suppressed.

26. On a personal level, my marriage has been a complicated one and we have had

**GRO-C** because of my infections. **GRO-C**  
**GRO-C**

When my daughter was born, I grappled with the uncertainty of whether I would die before we were able to develop a relationship or possibly before she could remember me at all. I lost my brother to liver cancer, he being co-infected with HIV and HCV as I am. His death was awful and he suffered terribly. It was distressing to have to share my grief with the selfish thought that that was possibly how I too would die. I have already had three mental breakdowns and now I suffer with clinical depression and hyper-anxiety that I would describe as akin to post traumatic stress disorder. However, it differs from PTSD in that with people like me the stress is ongoing. In America the condition has, I understand, been clinically re-named 'Continuing Traumatic Stress Disorder'.



27. In the late 1980s/early 1990s HIV/AIDS was all over the media and the papers, on *EastEnders* and with the Government 'tombstone' advert on billboards - you could not escape it. I lived with the constant fear of death and of being outed. Those known to be infected were ostracised. HIV was like the plague, the breath you cannot breathe. It was impossible for me to make medium to long term plans. Armageddon was coming. I was single and rich but my life was hollow. I was waiting to die. My death was imminent but my life was over anyway. It all seemed pointless.

28. C and I jointly owned and ran our own finance company/estate agency and were inextricably linked, not just through being brothers and the business, but as well by sharing the secret of our HIV/AIDS infection. Every decision I made was leavened by HIV and its impact not just on me but on C too.

29. C was insistent that no-one find out about our HIV status. We knew we would die soon. We sold some of our business interests (and were approached by other haemophiliacs' families to advise them on their finances in the event of their early death – which was very depressing work) and relocated what was left of our company to a country bolt-hole, away from people who knew anything about our past. My brother was already married but that did not deter him from pursuing a reckless, decadent lifestyle, seeing other women, gambling and using what he had in his armoury to exploit other people and make more money to spend.

30. I did not die and I married in 1990. I never explained anything to my wife. I just allowed myself to come to believe that I had somehow let her know – by some sort of osmosis. I cannot remember how but she found out that I had HIV in 1992. She had no idea at all and was shocked. She was as angry then as I have ever seen her. It was one of the most difficult and pressured times of my life.

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to me in those words just how sad she was for me and that she cared. Somehow, our relationship/marriage survived but we had to work out what my diagnosis meant for us. We have had a complex and difficult marriage with many highs and lows.

31. My wife and I wanted a family and there was no easy/safe way for us to do that in the mid 1990's except through the IUI sperm washing procedure. I transferred to the Haemophilia Centre at St Thomas' Hospital in 1992 after being referred to there for surgery on my left ankle. We approached The Fertility Department at St Thomas' about IUI. After many months of fertility testing and psychological assessments, we went before the Ethics Committee involving a panel pouring over our lives and making a judgment as to whether or not they considered it appropriate for them to assist us. When I was deemed as being unsuitable, because of the likelihood that I would soon die leaving a widow and baby, our marriage started to crack open again.
32. Some years later we were referred to, I think Dr Khan, at Birmingham University Hospital by Dr Savidge and were there given enough hope to attempt IUI again. Several months, up to one year, into the process I was told to see another doctor, I remember as **GRO-D** with a specialism in sperm testing. Dr **GRO-D** then told me that my sperm count was hopeless and I probably would not be able to have children. He then went on to say that that was 'a good thing' because a man in my position with just 18 months or so to live should not father children.
33. On the way home, I felt I had to stop for a period of time (I saw the Battle of Bosworth Field, signposted from the road and took off there) to try to absorb the news and prepare how I was going to tell my wife. She was distraught. Strangely, when we were called back for an appointment with Dr Khan to give us the final decision, we did not receive the negative news we both expected. He said 'You are approved for treatment, fabulous isn't it?' My wife went on to

become pregnant at the first attempt and our daughter born in 2002. Unfortunately, both our fathers had very recently died and I was sorry that, if we had been approved sooner for IUI they would have met their only grandchild. On the very day he died, although we didn't know it was going to happen to him, I did tell my dad that we were having 'IVF' and he was very excited about it. My brother and his wife had decided not to have kids because of the risks.

34. Around this time, I began experiencing the symptoms associated with peripheral neuropathy and was having a very odd feeling/sensation in my feet. I was also losing weight and feeling unwell. I happened to mention this to Dr Pao, Consultant at St Thomas' Hospital in Sexually Transmitted Diseases. He was immediately alarmed and called another doctor in for his opinion. They suspected peripheral neuropathy immediately and stopped the AZT that I had been prescribed in 1996 by way of HIV triple therapy. Dr Pao suspected AZT to have caused the problem. Dr **GRO-D** (a haemophilia doctor) had prescribed the AZT treatment although I was HIV asymptomatic. I do not believe that I had yet been informed of my HCV diagnosis in 1996.

35. The peripheral neuropathy was the start of some serious health issues for me. In addition to the pain and discomfort in my feet that I still have, I lost 2 to 3 stone in weight. I had to sit on a cushion because the bones in my bottom were sticking out under my skin. I later had facial surgery to fill out my face because I looked like a concentration camp victim. I now have limited mobility because I can barely walk on my feet. Moreover, I have arthritis in both ankles and I am now in constant pain. I am not allowed to take Ibuprofen and nothing works in terms of pain relief. I had no further HIV medication until 2005.

36. I had my first nervous breakdown in 2001. It was caused by a culmination of everything that had happened to me, including my health issues, the stress I was living under with HIV and being inextricably tied to my brother, doing a job I hated. I felt trapped in the job. If I left and found a 'proper job' ie working for

another organisation, I would have to reveal my HIV status as part of the application process and that that would either preclude me from getting the job or mean I was drowned in stigma. I had bottled everything up, my marriage was not as it should have been, I was worried about whether I would be a good enough parent and how much longer I would live. I was in a cocoon with my brother, sharing a massive secret, tied to a business with him, manoeuvred into dealing with customer complaints and doing all the hiring and firing of the staff so that he, my brother, could continue as front man to the business. I felt like a hatchet man. My brother was an extrovert and as well as a sociopath. I was turning into an introvert which I did not think I was.

37. I was unable to access psychiatric treatment on the NHS. I was told that there was a waiting list of around 18 months. I saw a psychiatrist on a privately paying basis. I wanted to leave the business but my brother's marriage had broken down. C couldn't or wouldn't buy me out and I ended up back at work. I was drugged up to the eye balls with anti-depressants.

38. I had another, bigger, breakdown in around 2005. An ambulance was called and I was led from my office in what I would describe as a catatonic state. At the hospital A&E, I lay sobbing on a gurney for hours whilst they tried to get to the bottom of what was wrong with me. Ultimately, I was given the option of being admitted to a psychiatric unit or going home with a prescription of Diazepam. That weekend, I went through with a pre-planned trip to London with my wife. There I had a psychotic episode. I believed I was being followed in London by a monster. The experience was very real and very frightening. It was one of the most disturbing experiences of my life.

39. I was very unwell for about six months and was diagnosed with depression and clinical anxiety. I had more private psychiatric treatment (again no NHS treatment available) then I went back to work. I felt like 'Humpty Dumpty', put back together again and sent back to the same life.

40. I started Interferon treatment to clear the HCV infection in 2007. I had to self-inject the Interferon in three places (leg, stomach and shoulder) every day, alternating between the left side and the right side of my body for six to nine months. I was on a fly-drive holiday in North Carolina with my family that summer and had to stop (wherever we were) at 3 pm each day for my injections. The side effects of the treatment were horrendous.
41. The clearing treatment was successful but my liver was already damaged. I have liver fibrosis and have an ultrasound every six months and a fibroscan every 12 months to monitor my liver. I experience a lot of anxiety during the ultrasound when the radiologist homes in and clicks at every image. The outcome of the tests always worries me. A cyst has been identified on one of my kidneys too.
42. My brother died of liver cancer in 2010. He had been in and out of hospital with pneumonia before they diagnosed the cancer. They discovered that that he had liver cancer and he died an unpleasant death within three months. I had my third nervous breakdown after the funeral. I just about held it together until after I had given the eulogy and did not return to work for around six months. When I did return to work I do so because of pressure to keep the business going.
43. C's life had been complex. After his death his widow and I learned things about him that we were not previously aware of. C had made decisions about the business without involving me. My brother had created our business and he was unique, a natural salesman. Whilst he was alive my personality had been suppressed. I was the Ying to his Yang. I had no affection for the business and felt I was continuing it for others. The company went into administration in 2012 and I retrained as a history teacher. I was amazed that I was still alive. Before C's death we talked about how we both separately thought that I would be the one to die first. I never thought I would survive for this long and, now that I have, that my life would be so constrained by pain as a result of the side effects of the HIV medication. I have now been compelled to give up my teaching career

because my pain levels do not allow me to concentrate long enough to teach. Through the previous business, I had managed to obtain life insurance (company death in service). I am, once again, no longer able to obtain life insurance or a mortgage.

44. I have had difficulty in finding and keeping a dentist willing to treat a patient with HIV and vCJD exposure and am often made to feel uncomfortable. In the last few years, two dentists have inadvertently pricked themselves with a needle that they had been using in my mouth. They were senior practitioners – they are experienced, skilful and careful – but still it happened. I did not stab them with the needle – I was a bystander, laid back in the chair, staring at the ceiling. I didn't even know what had happened until the treatment stopped and there was a kerfuffle in the surgery. The second time it happened a lady dentist was doing a crown and I was told by another, male, dentist that he had taken over and I would need to make another appointment. I was told that the lady dentist was in counselling now and would be starting a course of anti-viral drugs and would be off work for some time. No one considered what the impact might be on me – I was outside on the pavement within two minutes.

45. I am compelled to inform health practitioners that I am classified as at risk of vCJD. I am often in a shared area when having my blood taken for tests at hospital and am overheard by other patients. Expensive equipment used for invasive treatment has to be thrown away creating problems other people do not experience. I am passed like a parcel from dental service to dental service and none of them want the music to stop. It's horrible.

**Section 6. Treatment/care/support**

46. GRO-C



47. I have never been able to get the counselling or psychological support I need through the NHS – it always takes too long or has too many restrictions: they want measurable outcomes, but, for me, the outcome is maintaining the will to stay alive and that is never-ending. They don't value that, so, don't provide counselling for it.

48. I take as a matter of routine 12 tablets per day – 5 with breakfast and 7 after dinner. I also self-administer an intravenous injection every 48 hours. This is every day, every week, every year. People notice in hotels, friends notice when you go to stay – you need to ask for a lot of water! It's awkward and embarrassing. It's a lot of extra-packing when you go on holiday and a lot of extra-explaining to do at Customs. For the USA you need a visa, but, every time I go there they still insist in pulling you out of the line and putting you in temporary custody – under armed guard and separated from your family. It's scary. You are not wanted, you are a liability. And for this, I pay a fortune in travel insurance.

49. Whenever I present myself at an NHS facility, the same experiences occur – I have to 'declare' my various infections not forgetting my haemophilia, which, incredibly, it is very easy to do), recount my almost entire life story, recall the clinical name of every medication I take and prepare myself for any number of humiliating procedures and questions. I also have to often fight for the treatment I know I need. Surely it is not beyond the wit of the system to provide a central service for the ongoing care of people like me, which we can approach in times of need, confident that our records and special requirements will be met in a professional, timely and courteous manner?

## **Section 7. Financial Assistance**

50. In 1991, I received a payment of £32,000 through the MacFarlane Trust (MFT). I received the Skipton Trust Stage 1 payment of what I recall to be £25,000 very many years later.

51. I receive monthly payments through EIBSS augmented by PIP and some modest income as an A level examiner and through private tutoring.

52. When EIBSS came into force, I read the booklet and saw that the discretionary payment element was means tested based on our household income. I could see that I did not qualify for the discretionary payment because of my wife's income and did not bother to apply for that aspect of the payment. I was nevertheless bombarded with emails asking why I had not applied. Eventually I phoned EIBSS and asked that they stop emailing in response to which I was asked whether I would go ahead and apply together with a covering letter explaining my circumstances as the exercise would be useful to them.

53. I did so and approximately one month later I received a very rude letter in response confirming what I already knew – that I was not eligible and implying I should be grateful for the ongoing payments I was receiving and for which I did qualify – one of which had only been awarded to me because of the recognition of the decline in my hepatitis status. It inferred that I should be pleased to be even sicker because I was getting a bigger hand-out (notwithstanding the fact that I had had to complete myriad forms in order to apply for it and succeed in an appeal against their original decision). There was no acknowledgment of the fact that I had been invited to apply for the discretionary payment by the EIBSS themselves for their own purposes and that I was aware I didn't qualify. I didn't need a lecture.

54. On the 15<sup>th</sup> February 2019, I received yet another email from the EIBSS urging me to apply for a discretionary payment. The ineptitude and insensitivity of these people continues to amaze me.

55. I do not agree with the discretionary payment being means tested. My marriage is a complicated one and my HIV diagnosis is a sensitive issue for my wife. Without the discretionary payment, my contribution to the household is approximately £250 per month short and my wife is in effect being punished for

being married to me. My wife has been severely impacted in being at risk of being infected with HIV, my health, my breakdowns, my brother's death, the obstacles in having children and, now, financially. Why should her lifestyle be affected in any way by my HIV payments? I do not see the justice in the reasoning.

56. In January 2018, the MFT wrote inviting applications for grants to use the residue of available funds before they were wound up. It was quite a rigmarole in obtaining the quotes you needed to support the application. The deadline was February. I then found out that what was left was left would go to the Terrence Higgins Trust (THT). I managed to make telephone contact with the acting Chief Executive of the MFT. She informed me that the residual assets were £650,000 in cash and that it had already been transferred to the THT. She also confirmed that the total distributed in grants on the other hand had totalled just £450,000. I queried on what authority this decision had been made, and she told me that it was a decision made by the Trustees. I asked to see the minutes, but, was told they were confidential. However, she was happy to inform me that the transfer had been made according to the provisions set out in the Trust Deed, i.e. to go the benefit of 'those living with HIV'. I queried whether this was appropriate, given that the Trust was specifically set-up to benefit *Haemophiliacs* living with HIV, and she confirmed to me that, although that might indeed have been the case, the Deed was clear in instructing the Trustees to wind-up in favour of 'all people living with HIV'. I asked if the assets had been ring-fenced within THT for the on-going benefit of Trust beneficiaries, but, was told that this was impossible under the rules of the THT. However, she did say that THT had promised to appoint a 'liaison officer' – whatever that might mean.

57. At the time I accepted these explanations, although I remained unhappy about it. I felt that the original Trust was at fault and that there should be an investigation into the circumstances in which it was written and approved. However, it did occur to me that, at the time the Trust was set-up, there would be little

expectation of the Trust existing beyond the death of all haemophiliacs living with HIV and that that would, very likely, not be too far off in the future. There would be no expectation of the very unsatisfactory circumstances in which the Trust did come to be wound-up., or, indeed, that there would be so much money left. Indeed, the scale of the residue is astonishing, given the consistent claims of impoverishment emitting from the Trust whenever its was approached for help and the alarming correspondence it regularly issued to beneficiaries projecting the Trust's imminent financial collapse.

58. This was the context in which the Trust consistently made it difficult for beneficiaries to qualify for additional support and in which it applied the very strict criteria to all applications. Again, I always assumed this would be one of the original provisions of the Trust Deed. Imagine my surprise, therefore, when I was able to obtain a copy of the afore-mentioned Deed and discovered that virtually everything I had been told and assumed about it was untrue.

59. For one, I had not appreciated how closely involved the Haemophilia Society had been in the setting-up of the Trust. Nor had I recalled that the original 'grant' was £10 million (of which 6.5%, therefore, remains undistributed). Moreover, I could find no reference in the Deed to the actions the Trustees must take in the event of winding-up. In fact, there is no mention of winding-up anywhere in the document. Nor is there any direction as to how the funds should be used or the criteria which should be applied to applications for assistance. These draconian conditions were all self-imposed. Furthermore, the suggestions for the purposes to which the funds might reasonably be put are far more wide-ranging and generous of spirit than I ever remember being circulated by the Trust.

60. Clause 7 (xii) grants the Trustees the power to ... 'Make vary and revoke regulations' in connection with 'the appointment of committees ... for any particular purpose' (e.g., winding-up) PROVIDED THAT no such regulation shall override any provision of the Deed. I would argue very forcibly that – unless there is a later Deed that I am currently unaware of - the actions taken by the Trustees

in transferring all of the remaining assets to the THT are in fact unlawful as permitting the funds to be made available for the benefit of anyone not specifically cited in the original Deed is clearly an overriding provision of the Deed. Clause 12 of the Deed clearly gives the Trustees the freedom to 'supplement or alter or amend the provisions of this deed' for 'the more effectual execution of the trusts hereof 'PROVIDED ALWAYS' that nothing shall authorise any departure from ... the objects declared by Clause 4'. I contend the Trustees have departed from those objects and that urgent action needs to be taken by whomever or whatever is the appropriate authority to recover the assets for the benefits of *haemophiliacs* living with HIV and hold to account those who have allowed this wrongful omission on the part of the Trustees to take place.

### **Section 8. Other Issues**

61. Some haemophiliacs have been treated with manmade Recombinant FVIII for upwards of 15 years. Recently, a new consultant in my Centre queried why I was not using it. I explained that I understood it was simply a cheaper alternative to pooled factor and probably more dangerous and after my previous experience with HIV, I didn't want to take another risk with my treatment. He took the time to explain to me what the treatment was and why it would be beneficial to me. Apparently, it is much, much safer than the products I was still using, but, this had never been explained to me before. I switched immediately and also, on his further advice, changed to prophylactic treatment as that to had been under-represented to me as the safest option. It felt like *deja-vue* – I was still being kept in the dark.

62. Through my own failure to secure correspondence relating to the setting-up of the Inquiry, my daughter recently became unwittingly aware of my HIV status (she did already know I was an haemophiliac). She was incredibly shocked by this discovery and has GRO-C to cope with the trauma she is experiencing in connection with my health and prognosis.



63. Finally, it is a curious thing to be the subject of a Public Inquiry. They are uncommon phenomena – expensive and time-consuming I understand. I am familiar with two others – Hillsborough and Grenfell. The circumstances may, in the first instance, seem entirely different, however, I do feel an affinity with the victims of both – the Hillsborough victims went to a football match, they did not expect to become the subjects of a PI; the victims of Grenfell went home to bed, and, they too, were unsuspecting. I self-administered an injection and thought nothing more of it. Sadly, there are accidents when large groups of people come together and, similarly, there are fires. Medical mishaps are not unknown. But, those circumstances do not automatically lead to public inquiries. What these particular tragedies have in common is they weren't, strictly speaking, 'accidents' at all. They could, and should, have all been avoided were it not for a combination of malign official policy, negligence and conspiracy to cover-up and protect vested interest and reputations. This cycle has to stop repeating itself in British public life.

64. I am actually exhausted by my own continuing existence. I have realized that for sometime now, but, I was 'inspired' to include it in this statement by the fact that, a moment ago, I felt too worn out by my pain to get up out of my chair and continue this very document. I don't know what to do about that and, I very much doubt, that the Inquiry will be able to help me with it.

65. That may all sound rather melodramatic, but, the fact is, that since I became contaminated with HIV in my early twenties, the infection has dominated and directed my entire life. If nothing else, I would like to find out how that came to be so.

#### **Anonymity, disclosure and redaction**

66. I am seeking anonymity and would like my Statement redacted before publication. However, I understand this statement will be published and disclosed as part of the Inquiry. 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-B

Dated

21/2/19

## MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness statement has been prepared without the benefit of access to my full medical records.

03.11.1978 Hbs Ag neg  
04.11.1982 Test for anti-HBs ... positive  
02.03.1983 anti-Hbc positive, anti-HBs positive  
13.08.1984 "He is HBs Ag negative, anti-HBc positive, anti-HBs positive, and has no signs of active hepatitis. A screening test for circulating immune complexes was positive ...." (*Dr Swinburne to Dr Cuncliffe, Consultant Dermatologist*)  
23.01.1985 Date of first HIV positive result (*UKHCDO Patient HIV data*)  
06.02.1985 anti HTLV-III positive  
28.08.1985 "As part of my review of patients with abnormal liver biochemistry I would be most grateful if you could let me know the results of his liver function tests since 1980 since I note that they were persistently abnormal prior to that time." (*Dr Charles Hay (Sheffield) to Dr Swinburne*)  
02.04.1987 Referred to consultant psychiatrist at patient's request  
05.04.1990 "Write to Dr Black (new GP) DO NOT TELL GP OF HIV status" (*handwritten hospital note*)  
01.08.1991 "Told about HepC" (*handwritten hospital note*)  
20.12.1991 HepB Surface Antigen: Not detected, HepB Surface a'body: Detected, Hepatitis C Ig@ Ab: Detected