

IN THE INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF **GRO-B**

(NAME TO BE ANONYMISED)

Introduction

1. I am **GRO-B** divorced and live on my own in **GRO-B**. I was married to **GRO-B** to the mother of my children who are now adults. I was **GRO-B** diagnosed with severe haemophilia A at 18 months old. I have one older sister and two younger sisters, biological daughters of my parents who adopted me. My mother died in 2007 and my father in 2015.

2.

GRO-B

3. My medical notes run up to 100's of pages and my legal representatives are in the process of obtaining fuller records. Some of the plasma derived Factor V111 products that I have encountered include armour, alpha, cutter, 8Y, NHS, Travenol, FHC and EHF, to name a few. I have been prescribed other plasma derived products and recombinant Factor since infections, some of which will be on my medical notes.
4. Recombinant Factor was commissioned for people with haemophilia in 1996 on a roll-out, aged-based programme. Due to my age I was in the final phase of the process and despite constant requests to my centre and NHS commissioners via my then GP, I was forced to use plasma derived product for a further ten (10) years.
5. All the above (listed) products were prescribed at The Royal Free Hospital (RFH) in London in the early to late 1980's and are the relevant treatments regarding HIV and most likely HCV infection. Over the years I have been

- prescribed countless different plasma derived product but NHS records are scarce.
6. I was also treated with whole blood, unnamed experimental blood products, plasma, viper venom and cryoprecipitate at Oxford haemophilia centre from 1956 until approx. 1969. Oxford at that time had a small fractionation laboratory which manufactured Factor and experimental blood products which remain a mystery. I have asked more than once for details but been met with collective amnesia.
 7. Over the years hospitals have constantly impressed on patients the need for good home treatment record keeping and time and time again lectured us on the expense of Factor treatment. It's ironic that so many people's NHS medical notes are so sparse.
 8. I was also treated occasionally GRO-B at Shrewsbury Hospital approx. 1977/8 and twice at Edinburgh Haemophilia Centre in 1984.
 9. I have records from the RFH showing frozen blood samples last testing HIV negative 03/08/1982 and first HIV positive 18/09/1984.
 10. I have some medical records and my legal team are in the process of applying for all GP and hospital notes since birth. The records I have are disjointed and duplicated. Many years of treatment and appointments are missing despite two or three attempts to access further notes over the years. Many hospital inpatient and outpatient notes for procedures that remain in my memory from childhood onwards are non-existent and very few of my hospital stays are recorded. In approx. 1969 for example, I had my appendix removed under cryo cover at the RFH but I cannot find any records of this.
 11. Once my notes pertaining to late 1980's are sourced, it will highlight how much historical information is missing, years and years of my NHS treatment have disappeared. But as of now, I distinctly recall the following:

- (a) I have a letter from the RFH stating frozen blood sample first showing PCR positive for HCV 12/08/1980.
- (b) I was told at some point in the 1980's that I had been infected at Oxford with HBV as a child. To my knowledge I have not been affected adversely by HBV but I don't know this for sure. My parents were not told that I had hepatitis via treatment despite showing an active interest in my care as shown by heartfelt letters in some of my medical notes.
- (c) No warning had been given to me or my family at any point that I was at risk of HBV, HIV or HCV including any other pathogens through using cryoprecipitate or Factor V111.
12. I was infected through treatment of NHS Factor V111, either via an injection by my mother, myself or a health professional. According to my records from the RFH my positive HIV status was mentioned at an appointment on 04/06/1987. I just vividly remember being asked at some point "do you want to know your status". I said "yes" and the doctor came back into the room and said, "I'm afraid you are positive". I am sure I was first told before this date, most likely pre 1985 GRO-B and life changes are strong in my memory. As stated, medical records are patchy and confusing. One would have hoped and expected copious notes when being given such important news.
13. Whenever I was told, I vividly recall asking all sorts of questions of the doctor, "Will I die? What does this mean? Is there a cure? Why has this happened? When will I die? What's going to happen to me?"
14. At that time all I knew was that infected people were dying a few years after diagnosis, and dying a horrible, painful and scary death. This, I gleaned from sensational media coverage and government leaflets, not from my health carers. Information from my doctors was pretty much non-existent.

15. I was given no answers, clinical or otherwise other than, "don't have sex or if you have to then use two condoms". This may have been at a later date or it may have been at this appointment, I don't remember. I wasn't given any information to help me manage and understand the infection.
16. I feel very strongly that I should have been asked if I wanted my blood tested for anything, let alone something as scary as this with no treatment or cure. It wasn't called HIV then, it was called HTLV 111. I have very strong views that I wasn't asked. It was a nightmare.
17. I have realised since that my doctors (specifically Prof C Lee) were doing research on their patients including myself and this makes me feel even worse that I was tested without informed consent and not told for some time. Writing this now brings back dark memories.
18. Over the next few years I remember attending many, many appointments and asking questions of my doctors and nurses. Looking through the notes I have for that time I don't recognize myself. There were conversations where I was obviously scared, alone, and frightened and trying to make sense of my situation. In hindsight, it was crazy expecting the Haemophilia Centre which had infected me to be able to also support me through these dark times.
19. Two positive memories I have are the sessions with a counsellor called Riva Miller. Riva had a direct counselling approach which I railed against at first but kept going back for more. Her view was that we have to accept the things we can change and those we cannot change. The way to deal with my infection was to accept I could not change it but I could put strategies in place to live as positively as possible with my diagnosis. I gradually got it and although progress was initially slow and my fear didn't go away, I took steps to change the way I was dealing with the situation - strategies that I still use to this day.
20. The second positive memory I have was going to the Centre with a mild chest infection (any cough, cold or unusual ache or pain would have me thinking this was the end and I'd be at the GP or Haemophilia Centre) where I saw a younger

doctor, no doubt on secondment. He sorted out some antibiotics but also asked me how I felt about my diagnosis. He basically said: "hey we don't know much about this virus but although it looks depressing, medical advances can be made and maybe it's not as bad as it looks". I think it helped that he wasn't part of the regular Centre staff. It was all a bit institutionalised at the time and patients weren't encouraged to look outside the haemophilia world for support. I do recognise the effect our infections had on haemophilia staff in hospitals. Some of them made grave errors, some were lazy; some trusted too much and didn't feel able to ask questions themselves; some I will be happy should the Inquiry serve to ruin their reputations. However, a major mistake was made following this nightmare. Leadership amongst haemophilia professionals seems to have been non-existent. There was little in the way of doctor/patient communication.

21. I remember using a lot of Factor around this time. Ironically I was only just coming to terms with my bleeding disorder and took years to overcome the fear of sticking a needle in my veins. I used alcohol, recreational drugs and any morphine based prescription pills I could get. I don't know if this was because of the physical pain caused by bleeds, the social, emotional and mental issues surrounding haemophilia plus news of my infection or just part of who I was. It doesn't really matter to be honest, it was a strategy I used and I needed all the distraction I could get.
22. I was physically active, had a demanding job and never really considered stopping prophylactic and on demand treatment with Factor. I remember being very aware that I was probably injecting myself over and over again with HIV but advice was to carry on with (probably still infected) product until the new heat treated product came along. A very strong memory is the excitement from the nurses when heat treated product came along (I have no idea of the time scale and in hindsight heat treated factor should have been financed years earlier as the technology had been available for many years). I remember thinking well, OK that's good but isn't it a bit late?

23. My relationship with the Centre and particularly Prof C Lee (who took over the directorship when Dr C Ludlam had a heart attack) quickly became hostile. I was working [GRO-B] in South London and would go to the Centre on my way home on a regular basis to pick up Factor. It feels obvious now that I had a need to stay close even though I began to hate most of the staff. There was little in the media about AIDS other than death and discrimination. We were a backdrop ("innocent victims") and I guess the only place I felt safe talking about it was at the centre. I think I hoped that one day they would say, "good news: [GRO-B] We have found a cure!" They didn't.

24. Anyhow, I was prodded, poked and grilled about my sex life. I remember that well. I was made to wait up to three hours for my Factor for reasons I still cannot fathom. The staff would say they had to wait for a porter to go down to the fridges so I would just wait at reception, often with other patients who I never spoke with. It was surreal and shows how scary the whole thing was. Eventually, Riva Miller helped me to understand that maybe a change of scenery would help. Moving to another Centre wasn't something I [GRO-B] really thought about until now. [GRO-B] The only real sensible option was to transfer to St Thomas' Haemophilia Centre (GSTT) which although further away from home was a Comprehensive Care Centre (CCC), which could offer the same clinical care as RFH.

(a) (A further memory from this time is the regular "check up" at the centre. I would be led into a side room and asked to strip to my underpants. The doctor would eventually come back and proceed to check my body for signs of AIDS. This was pretty basic and looking back they were checking lymph nodes for signs of swelling. I just remember being petrified that something would be found and the sheer horror of those check-ups remain to this day. I'm no psychologist but I am sure most of us have some form of PTSD.)

25. I would say that the move to GSTT was one of my better decisions. I hope the Inquiry looks at the aftermath in Haemophilia care in terms of how we as patients were affected. To trust in the same people who had let you down was

a massive issue and some residue of harm must still linger in many of us still alive.

26. The Haemophilia Society, the only UK organisation supporting people with haemophilia, were taking medical advice and guidance from the UK Haemophilia Doctors Organisation (UKHCDO). This organisation were incredibly slow to realise the risks, (we can see now that they had the evidence from years before through markers for HBV) and Prof Lee stated the chance of infection was 1 in 1000. She also tried to make me go on a trial of a drug called AZT which, at the doses recommended, may have hastened many people's deaths. I declined the trial and recall challenging Prof Lee in a group patient meeting to discuss it. This was one of the first times I met with other patients and most people were silent. I spoke up, expressing my anger that we had been infected and all they could offer was a trial of unlicensed, highly toxic medicine. Prof C Lee's reply is one I won't ever forget. She said, "think yourself lucky you don't live in America, you get free treatment here in the UK which you wouldn't get there".

27. To describe all the emotional and physical effects of my infections with HIV and HCV plus HBV and "at risk for vCJD" would be impossible. It has changed my life completely and although I will do my best to explain, there are some parts which are so dark I hesitate going there.

HCV

28. I have undergone two treatments for HCV. First Interferon and Ribavirin in 2010 which failed after 6 weeks when the clinical depression, exhaustion, and various other side effects caused me to stop as I couldn't face a further 14 months. I thought it would kill me and I certainly would have been so badly affected it wasn't worth continuing.

29. The second time was Oct/Nov 2015 with Ribavirin and Sofusbuvir. I completed the 12 week treatment and suffered the same clinical depression and exhaustion. Although the success rate was better than 95 %, I still tested PCR positive following blood tests in Feb 2016.

30. I wanted to access the treatment six months earlier **GRO-B**
GRO-B but NHS England
wouldn't pay for it. I had to fight through my Hepatitis C doctor, MP and other
sources to access the treatment. I was about to buy generic treatment from
India when after 6 months I was finally offered it on the NHS. I have found out
since that I could have been prescribed an alternative to Ribavirin but wasn't
because it was cheaper than a non-side effect alternative. **GRO-B**
GRO-B

31. I maybe have one last chance of successful HCV treatment but I don't know if
I am ready. I am putting off a liver scan at the moment because I have a very
bad back which is only just improving.

32. Access to HCV treatment, for a virus given to me by the NHS has been, and
continues to be a nightmare.

Co-infection – HIV and HCV

33. I have been on various antiretrovirals for HIV since 2003 **GRO-B**
GRO-B The various treatments
had to be changed over the years because of side effects, including diarrhoea,
extreme fatigue, incontinence, hallucinations, swollen joints, depression,
headaches, and so on.

34. HIV is suppressed in my body now but I have also suffered osteoporosis and
body/face fat distribution which is horrible. I have regular "newfill" treatment
which consists of injections into my face. I am limited to how many I can have
and on occasion have paid privately at the cost of £700.

35. The effects of co infection with HIV/HCV are worse than the effects of just one
virus and of course I still have HIV and HCV, just that HIV is currently
suppressed. I was also infected with the herpes virus via contaminated blood. I
think most of us were, but no one talks about it.

36. All of the above have caused depression and mental health issues. My current Haemophilia Centre has offered, indeed encouraged, antidepressants. However, I choose to use talking therapies and/or alternatives to antidepressants.

37. Dental and other care has been compromised by my infections as most dentists won't treat me, especially due to my "at risk" status for vCJD. As I get older, I get general medical conditions such as enlarged prostate which are compromised because of my infections.

38. The above clinical consequences are not exhaustive and I find it all very draining to live with.

Impact on family and life in community

39. Since my infections, I have told few people the true situation. When I was first told of my HIV status, any relationship became a nightmare and although I wouldn't blame my infections for my divorce, they sure didn't help.

40. My ex-wife and I tried to get help with sperm washing in order to have children. We were told it was too expensive and we shouldn't really be having kids anyway. I researched the clinical issues around transmission and found out that as long as HIV was inactive, the risks of heterosexual sexual transmission were almost zero. So we decided to try for children naturally. My haemophilia centre were aggressively obstructive in this and of no help at all. We conceived naturally despite most health professionals we asked for help being dead set against us doing so.

GRO-B

GRO-B

41. Basically most of my life from my late 20's onwards has been affected by my infections. I was forced by discrimination to firstly leave a successful career **GRO-B** and then by ill health to give up a second career **GRO-B** I have been unable to work (other than in a voluntary capacity and then I had to keep it quiet in order to try and claim benefits) since 1991.

42. I never told my parents. I only told **GRO-B** a few years ago **GRO-B**
GRO-B
GRO-B My life since infection has been a lie. We never told schools, neighbours and friends due to the extreme discrimination which is still an issue but was horrendous many years ago.

43. I hope the Inquiry team understands that not everyone will be delighted about their work. For many, it is a reminder of what happened and brings to the fore, feelings and emotions they would rather not revisit. A big part of me feels like that. I have worked through the issues and exploring my darkest moments isn't necessarily a good thing. My decision has been to embrace the Inquiry but that doesn't mean it's easy or maybe even healthy.

44. From 1991 when I was forced to give up paid work, I have encountered the nightmare which is claiming DWP benefits. Since that time, up until the announcement of the Inquiry, the benefits system has fought me all the way. I have had to provide multiple medical letters at regular intervals; had DWP visits to my home on many occasions; had benefits stopped or lowered because the DWP would not accept haemophilia and HIV/HCV as a good enough reason to be unfit for work. This is partly because HIV is considered a "long term treatable chronic condition" and HCV and haemophilia totally misunderstood. Long term HIV co infection with HCV is NOT a "long term treatable chronic condition" and haemophilia makes it even worse along with ageing and consequent liver damage.

45. Over the last 12 months and since the announcement of the Inquiry and Group Litigation Order, the DWP has suddenly decided to leave me alone and I now have full disability benefits returned. However, I have had to fight tooth and nail for these with the help of a Welfare Expert and it has taken years and years to achieve this at some emotional, mental and physical harm to myself. The situation was particularly difficult [GRO-B] as bringing up children is expensive and the DWP kept trying aggressively to make me go back to work.

46. If it hadn't been for my family supporting me in times of need I don't know how it would have worked out (remembering of course that my family probably thought I was a lazy spendthrift when actually I was unable to work but didn't want to tell them why).

Financial effects of infection

47. [GRO-B] took retirement on health grounds from [GRO-B]

My employers knew my HIV status and that I had haemophilia; however the situation wasn't easy, the job and five hour daily commute was too much and I had to accept I had no other option.

48. The following financial information is not definitive and depends on memory as I have no records from this time. However, the Inquiry will be able to access detailed records from the MFT.

49. In around 1989/90 following Justice Ognall's decision not to continue Legal Aid for the group legal case, the John Major government set up The Macfarlane Trust (MFT) initially to make an ex gratia payment of £20K to each person with haemophilia who had been infected with HIV. This was followed by a sliding scale of payments to "registrants" (later to be changed to "beneficiaries") depending on marital status and children. I remember the MFT requiring birth certificates when I applied for the second payment, as their office didn't believe me [GRO-B]

50. Registrants who were babies or children under 16 or 18 years old were paid via their parent/s who were to either hold the monies in trust or spend to the benefit of the registrant. Anecdotally I have heard from young men who did not receive this payment and did not even know about it.
51. The government did not accept liability for our infections, which is why the payments were ex gratia. This situation has not changed and the events around Alliance House organisations should be a priority for the Inquiry to investigate.
52. The MFT then began paying small regular ex gratia monthly payments and registrants could also apply for one-off financial grants for white goods, motability scheme deposits (only for Motability vehicles which not everyone wanted to be part of), holidays etc. So began an unfair and discriminatory financial system based on charity, not need, from an underfunded and poorly run hardship fund.
53. In a nutshell, this system was arbitrary and discriminatory. The Trust was set up as a charity with Board of Trustees overseeing an office staffed by people whose job was both administration-based and to decide if a particular grant application should be accepted. There were regular Board meetings where Trustees discussed the merits or not of grants that were deemed unacceptable by the office staff. So, some people didn't want to apply for grants as they felt it demeaning. Some applied for every grant going (including some that weren't on the list) and in between were those who practically couldn't apply and/or didn't have a supportive Haemophilia Centre to help them apply.
54. The MFT continued until the current EIBSS scheme was set up a couple of years ago. Initially the Board were made up of current or ex Haemophilia Society (HS) Board members, plus what I think were DoH choices. Either way the charity was staffed and run by people who quite frankly have not been up to the task.

55. There was a period of a few years in the mid 2000's when the MFT Chair (Peter Stevens) and CEO (Martin Harvey RIP) were more helpful and included registrants in their efforts to gain more generous funding from the DoH. I was part of a group who developed residential weekends for those affected, funded and supported by the MFT. These included both practical and emotional projects plus most importantly an opportunity for us to meet each other and gain mutual support and information. These events were incredibly helpful to those who attended.
56. We worked hard to enable them in the first place. They were supported for a number of years. They were well attended although not for everyone. Campaign issues were often discussed on a formal and informal basis but the main reason for events was mutual support. Personally, my involvement was beneficial. I was able to use my skills to help both myself and others to make some sort of sense of the circumstances we found ourselves in.
57. These events and registrant involvement were abruptly halted in about 2011 when Roger Evans became Chair of the MFT and Jan Barlow CEO of the Alliance House organisations. The circumstances around the ending of dialogue with registrants/beneficiaries should be thoroughly investigated by the Inquiry. We had a lifeline in the form of non-financial support which was taken away and I will never forgive those involved for treating our group of vulnerable people so poorly. The MFT were a registered charity whose stated purpose was to support those infected and affected by contaminated blood products. Instead, they caused untold harm to an already vulnerable community. In about 2012 a small group of us wrote a Letter of No Confidence in the MFT Trustee Board, which we circulated to the DoH, Charities Commission, Haemophilia Society, MP's and many more. The letter was signed by those beneficiaries we were able to contact and basically ignored by anyone with the power to help.
58. In the years since the MFT was set up I have received regular monthly payments and a number of one off grants for various white goods, respite breaks etc. I also received £20K as an ex gratia payment when the Skipton Fund was set up for people infected with HCV. Before I received any money

from the MFT in 1989 I was required to sign a waiver to say I would not take any further legal action regarding infection with blood/blood products with HIV or any other virus. I didn't feel I had a choice so I signed. It took 11 months from the announcement of the Skipton Fund to the first payment.

59. To work out exactly how much I have received from the MFT would be very difficult. The amount I have received has meant I managed to live outside poverty over the years. The process of applying was slanted toward those of us with supportive hospital doctors and no shame. It was demeaning, unfair and the goalposts were always moving. I have made my feelings about the various organisations clear. The government of the time didn't expect us to live for long. They knew we had been at risk of NANB hepatitis, which is why I had to sign a waiver. I don't really know what more I can add. Looking back, it's surely not coincidence that the EIBSS was set up around the time the Inquiry and GLO were announced and financial assistance suddenly improved. The process of applying to the EIBSS was and is still time consuming, demoralising, difficult, dependent on haemophilia centre support and although an improvement on the MFT, extremely unfair.
60. Other than being infected with HIV and HBV/HCV plus being "at risk" of vCJD, I have no knowledge of other infections via blood products. However, as I become more aware of the circumstances surrounding my infections it wouldn't surprise me if I hadn't been infected with other viruses and/or pathogens.
61. I could sit here all day and describe situations where my infections have affected my life medically, emotionally, financially and socially. I am lucky that my family were able to provide me with the financial and emotional means to live with the horror of what happened to me. Without their financial support, I dread to think what might have happened to my life. I missed loads of my early education resulting in very few academic qualifications. However, I feel the support my family gave me when I was younger, has helped me and given me whatever it is I have emotionally, practically, and financially to get this far.

62. Counselling and support has been patchy over the years. I have had to fight continuously to make a life for myself and I still have to manage my conditions within an NHS that has veered from excellent to dreadful. I still have HCV and the scary appointments will never end; waiting for scans and blood tests to come back; not knowing if the next appointment will be the one where my consultant tells me I have liver cancer.
63. It's also wearing on both body and mind let alone wallet to always have to travel into London for my specialist appointments. I am currently well overdue a liver scan but have been unable to travel into London because of illness. I want to move to the **GRO-B** Country. I am **GRO-B** years old and would love to "retire" somewhere I love and away from the city, but I don't know if that will be possible.

This inquiry

64. What happened to me should never have happened. What happened to me since is worse. Originally I didn't welcome the Inquiry, I felt it had come too late; that I didn't want to go back again and look at the horrors but now it's started, it's not easy but I welcome the opportunity to help Sir Brian and the team do the best job they can.
65. I understand the Inquiry used its powers to demand transcripts of Haemophilia and HIV Living Stories from the British Library. Among them is mine **GRO-B** **GRO-B** I was going to send the Inquiry these transcripts with this statement. The British Library wrote to me but I have since moved so the letter will have gone to an old address and it's possible a stranger opened the letter.
66. I have copies of my medical notes which are all over the place. However, the most important are copies of frozen, stored blood samples showing a window when I was most likely infected with HCV and again HIV.
67. I am a private person, **GRO-B** The discrimination of the 80's has gone but my HIV status particularly is not something I wish to broadcast.

68. I am happy for this statement to be published with redactions including my name and any other obvious information which would affect my desire to be anonymous.

STATEMENT OF TRUTH

I believe the facts stated in this Witness Statement are true.

Signed: GRO-B

Dated: 1/2/19