

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN5401001

Exhibits: WITN5401002

Dated:

17/6/2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 February 2021.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name GRO-B. My date of birth is GRO-B 1965 and my address is GRO-B. GRO-B. I am a sales office manager for a company that manufactures wooden pallets. GRO-B.
2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I believe I contracted as a result of being given blood products to treat haemophilia.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on my life.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. I had a major bleed in my ankle at around the age of 7, I twisted my ankle and it kept getting bigger and bigger as a result of the swelling. I recall my mother having an argument with the GP.
6. She was told that it was just a sprain, but she made herself very tall and demanded a second opinion because she recognised the joint being similar to what her haemophiliac brother had experienced. The doctor refused a second opinion at that time.
7. Another GP in the practice, Dr GRO-B, asked what the commotion was and ushered my mother and I into his office. He had conducted some research into bleeding disorders and after examination of my ankle, I was whisked straight to Huddersfield Royal Infirmary for blood tests. Following those, I was diagnosed as a low-level carrier of haemophilia A, with a low clotting level – a quirk of nature.
8. I ended up with quite bad ankles and spent my life into my teens relying on crutches to walk. I could not participate in sports at high school and I was not allowed to play outside, in case I got knocked.
9. I would receive factor products ahead of minor surgeries and for dental extractions (which took place in hospital) I had to take Factor VIII. I did not receive Factor VIII products very often and I was never given product to take home. Overall, I would say I have received product less than 50 times – the last being for a liver biopsy.
10. I remember a couple of different products – some came in a bag and was administered by drip, sometimes via syringe. I referred to cryoprecipitate as like a 'slush puppy' when it was brought out before being heated with a Bunsen burner.
11. Due to wanting to start a family, I was offered genetic counselling. At this time I was advised by a genetic specialist that if I became pregnant to terminate a pregnancy if I was carrying a boy. I was devastated about this. When I found out I was pregnant in 1995, my husband and I went to find out the gender of the baby.

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We were asked why we wanted to find out, with it being intimated that we were trying to choose the gender and I recall [GRO-B] saying that it was not so that we could paint the nursery but to be prepared for a haemophiliac son, if that was the case. He was so upset that he ended up leaving the appointment.

12. A Chorionic villus sampling (CVS) test was carried out to determine the gender of our unborn child, with a test for haemophilia from the same sample, in case it was a boy. There was a 50% chance that he would have haemophilia – my mother and her two brothers are the perfect example. My grandmother was a carrier, my mother was a carrier, Uncle [GRO-B: U] was a haemophiliac and Uncle [GRO-B] had no haemophilia at all. My own family tree allowed me to have faith in the 50/50 chance. During the procedure, a needle is put into the foetus to take a blood sample. I was informed that there was a risk of damage and miscarriage, but I spoke to Mr Feeney my obstetrician and he commented that if I was meant to lose the baby, sometimes it is mother nature's way – he was very empathetic and supportive.
13. A week after the test, it was confirmed that our baby – whom by then we knew was a boy, had severe haemophilia A. As soon as the news was delivered (I would have been 12 weeks pregnant), I started getting on the telephone – I rang the haemophilia society (I was not a member at the time) to put me into contact with other mums and I spoke to my haematologist, Chris Carter. He put me in contact with Alex Hamilton, a paediatrician at Huddersfield Royal Infirmary, who told me to come in for an appointment where he explained what they would do for a haemophiliac child. My husband and I went knowingly ahead with the pregnancy after speaking to all of those people.
14. I went for a routine haemophilia clinic appointment in December 1995 at Huddersfield Royal Infirmary. They took blood to check everything was fine and I was informed that I would be tested for HCV because a test had become available (but the results would take some time to come back). I do not recall them explaining why.
15. My son was due to be born on [GRO-B] 1996 and my pregnancy had to be controlled carefully because of my haemophilia and that of my unborn son. An

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appointment was made with the obstetrician to go through the protocol ahead of time, for when I gave birth. This appointment was on Monday GRO-B 1996.

16. On the Friday evening prior to the appointment, I received a phone call from my haematologist, Chris Carter to say that my results were back from the December tests. He informed me that I tested positive for HCV and that the virus was live and active. He said that he wanted to tell me on the phone rather than wait for a letter and at the time I thought it was nice of him to let me know because I did not see him very often. I do try to see the good in everything rather than the bad.
17. I was not provided with any information on infection control. I am very conscious not to share razors and toothbrushes, but that is because of my own common sense and practice.
18. It was my nephew's birthday on Sunday GRO-B and everyone was asking how I was in regard to my pregnancy. I found it very overwhelming because I was still in shock about the HCV.
19. For the avoidance of doubt; I have no tattoos and I have never used intravenous drugs. There is no doubt that the infection came from the blood products I received for my bleeding disorder.
20. I drove to the hospital on Monday GRO-B for the appointment, experiencing what I thought was Braxton Hicks, but it soon transpired that I was in labour. I was put in a wheelchair and I turned to the obstetrician, Mr Feeney that I had tested positive for HCV and that it was live and active. This put everyone into meltdown – I was ushered into a separate room and an infection control lady came in. I cannot remember her name but she seemed very ill informed, perhaps because not much was known about HCV.
21. All of the medics in the delivery room were double gloved and masked. Fortunately, our son was delivered normally. My son was placed on my chest so that I could feed him and I distinctly remember Mr Feeney walking in and shouting 'get that child off the breast now'. He asked how long I had been feeding him, to which I explained he had not yet latched on. He remarked 'thank God, because that is when antibodies will be passed on.'

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22. After I had given birth, I was told that I was not allowed a shower or a bath. I can only assume that it was an infection risk.
23. After [GRO-B] came along, Chris Carter said where was some recombinant (synthetic and non-human) Factor VIII for [GRO-B] in the path lab. He told me to not let [GRO-B] have anything else other than the recombinant product because it was a safe supply. I found Chris Carter very nice and supportive. I spoke with another family whose son was receiving human factor products and they were looking at taking the hospital to a local panel because recombinant product was available. When I became aware how hard that family were fighting for their child to receive recombinant, I knew the human product carried a risk.
24. My husband and I built a treatment room for [GRO-B] at home because his treatment had to be administered in a sterile environment. He had his first treatment under the age of 12 months.

Section 3. Other Infections

25. I have not contracted any infection other than HCV as a result of being given contaminated blood. Retrospectively, I found out that I was tested for everything and anything.
26. I received a letter on 29 September 2004 from Calderdale and Huddersfield NHS trust explaining that at some point I could have been given blood products containing vCJD. I exhibit this letter as **WITN5401002**. It stated that I would not find out if I had been infected and therefore another concern was added to my list of worries. Within the same envelope was an identical letter (same date, same hospital reference number), but it was addressed to another individual in Huddersfield. This was obviously mistakenly added to my letter when put into my envelope and I felt this was a severe breach of confidentiality. I called the hospital to inform them of this and to send out another letter to the intended recipient. I kept the letter because it was attached to mine.

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27. Along with the letter was an 8-page information booklet explaining what vCJD was, the reasons why I was being contacted, along with advice as to what would happen if I started to develop symptoms. I was told not to be a blood, tissue or organ donor and to inform medical professionals of this.

Section 4. Consent

28. I never specifically consented to be tested for HIV, but I became aware that I had been tested because it was on my medical records.

Section 5. Impact

29. I like to think that I am a 'can do' kind of person and I try and see the best in any situation. I did feel very tired before and after [GRO-B] was born, but I put any symptoms of HCV down to the fact that I was working and had a young child who was in and out of hospital – I spent many a night at the infirmary as he suffered with major bleeds. I did not know any different. My husband worked nights, which worked well when I went back to work and if [GRO-B] had any hospital stays we would plan that between us.
30. I was offered a 12-month course of Interferon and Ribavirin in 2003.
31. As a precondition of the treatment, I had to be sterilised and take an extra form of contraception. I also had to have a minor procedure where the lining of my womb was burnt and a Mirena was fitted (a long-term coil that is sewn into the uterus). This was all due to the implications of becoming pregnant whilst on the medication. I believe that my husband and I would have had more children – yes things were difficult with a severely haemophiliac child, but I have always said I would rather have [GRO-B] with his haemophilia, which was against initial advice than another subsequent child without. We had not definitively decided on more children, but the opportunity was taken away from us – if I wanted the treatment, I had to be sterilised. This is yet another aspect resulting from being given contaminated blood product(s) that we have to live with.

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32. Quite fortunately, [GRO-B] has a half-brother from my husband's previous marriage, who is 11 years older and they are very close. Nevertheless, I am sure [GRO-B] would have liked a sibling who was at home all of the time and closer in age. I have always treated my step son equally to [GRO-B], never any differently.
33. I was taught how to self-inject the Interferon, which I found dreadful. I timed the injections for a Friday because it would completely wipe me out and I would need the weekend to recover. The treatment was horrific and I have never been the same since. I suffered with anxiety and extreme fatigue and I lost hair during the 12 months – it would fall out every time I brushed it. The treatment was far worse than any symptoms of HCV that I had at the time.
34. I continued to work whilst on the medication – my rationale was that if I did not wake up for work, I would not wake up at all. I worked for the same employer as I do now and they were very good and supportive. I also had very good neighbours and friends who helped with [GRO-B].
35. I had regular check-ups during the course of treatment and at 3 months I was told that my viral load had dropped significantly. At 12 months it was still low, but 6 months post treatment it came back. I was devastated as I had put myself through complete torture. I was under Dr Sobala for this treatment - he worked between Calderdale and Huddersfield Royal Infirmary.
36. I did not undergo a second round of treatment until 2013 – my understanding was that I just had to wait.
37. I have a copy of a letter from Dr Sobala to the Viral Hepatitis Nurse dated 26 March 2013 regarding my second course of treatment. I started a course of Pegylated Interferon, Telaprevir and Ribavirin on Monday 13th May. Every 8 hours I had to consume 80g of fat and I was given a bottle of liquid fat in case I could not consume the amount.
38. A recognised side effect of Telaprevir was rashes and within a week I developed a significant rash and the treatment had to be aborted. I immediately went in to see Dr Sobala – he asked for me to remove my clothes (my husband was in the

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room with me) as the rash was all over my body. I was instructed to stop the medication straight away, but I still retain residual marks of the rash, which resembles prickly heat or little red 'spider veins', as I call them.

39. Dr Sobala told me not to worry because there would be new treatments available soon, for which I would be considered. He was very flippant and I found his attitude uncaring – he was not concerned and felt that I would be ok despite how I was feeling. I went to my GP, Dr [GRO-B] because I was not happy with the comments and the attitude of Dr Sobala. After GP intervention, I was told that I would not have to see him again and my care was transferred to Dr Southern at Bradford Hospital.
40. In 2016, I was told by Dr Southern at Bradford Hospital that there was a new drug available (Harvoni), but it was very expensive. He remarked 'if they will not fund your treatment, I will fight for your funding because the NHS has given this infection to you.' Funding was provided and I completed a 12-week course of tablets.
41. I had no major side effects with Harvoni and I found the treatment a walk in the park compared to the previous medications. I was tested every couple of weeks and my viral load was decreasing dramatically. At 12 months the HCV was undetectable and it remains so today.
42. Following the treatment in 2003, I have not been physically and mentally the same as before and I still suffer with residual effects. I am extremely anxious, suffer from bouts of depression and I often break down in tears. I have brain fog which I feel is not lifting and I feel that I am an emotional liability. I am unable to do many of the activities I previously enjoyed. I feel exhausted, constantly fatigued and rely on my family to do household work. I suffer with terrible headaches and am more susceptible to infections and viruses. I constantly worry over whether the HCV will return. I no longer like being left on my own – so much so that my husband has changed his shifts after 30 years.

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43. I had no history of mental illness prior to my HCV infection and treatment. I would not wish my experience on anyone – to go through a horrific course of treatment, which fails to clear the virus. As I have stated, I have never been the same since.
44. I have been diagnosed with probable MGUS (Monoclonal Gammopathy of Undetermined Significance) and IgG Lambda para proteins and both were not present prior to my HCV diagnosis. These conditions have not knowingly caused me any issues so far but I am told they could potentially result in cancer. Though my levels are low, I am supposed to be monitored annually. This has not happened during the Covid -19 pandemic.
45. I have had at least 2 liver biopsies and 1 Fibroscan, though apparently I am too slim for there to be a reliable result with the Fibroscan. I require to be administered with factor product before the biopsies, along with tranexamic acid and Desmopressin, otherwise known as DDAVP. Initially the result was 0, but the last time I had a biopsy (March 2013) it has progressed to level 1 – early stages of fibrosis.
46. My liver function tests have been fine, although throughout the pandemic I have only had telephone consultations with the nurse.
47. There is a stigma attached to the virus, but I told everyone at work because I thought it was the right thing to do. The majority of my colleagues have been there for years and the directors are the same from when I started. That said, there was one colleague (who was also a neighbour of mine) that refused to pick up my cup due to infection risk, so I had to explain what I knew about the risk and that she could not catch HCV through holding my cup. I did find that difficult.
48. I had my wisdom teeth taken out in my early 20s (mid 1980s). This would have been when the 'AIDS Don't Die Of ignorance' tombstone adverts were on television. I had infection risk stickers on my medical file, presumably because I was a haemophiliac. They may also have known that I had had an HIV test, which even though it was negative, the mere taking of a test in those days would have put me in a high risk category. I remember a few of the nurses refused to go into theatre. A friend of my then husband's mother was one of the theatre nurses and

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she told the others to stop being ridiculous. They all double gloved throughout the procedure. I should add that I cannot ever remember consenting to an HIV test.

49. I recall the big yellow stickers stating 'infection risk' being on my medical notes, as a result of being tested for HIV. To clarify, this was before I was knowingly tested for HCV. I found the stickers a bone of contention because my HIV test was negative, but I accepted it at the time, as I knew know better.
50. When I applied for a mortgage, I had to take out a separate policy because I had been tested for HIV – even though I had a negative test result.
51. The nurses on the ward also refused to change my swabs because of the HIV test – even though the test was negative, so I had to take them out and change them myself. I vividly remember a man who was brought into the ward from A and E – he had been involved in a road traffic accident and was covered in blood. The nurses were all over him and I remember asking why they refused to change my dressings when I had confirmation that I did not have HIV, yet the HIV status of that man was unknown.
52. I told everyone in the family about my HCV infection and they were very supportive, but I feel that they have no appreciation of what it involves because they are not living through it. I could ring my sister up at any hour and she would be there for me – I love her dearly, but she has never been in hospital, never had any children and therefore never experienced the anguish of passing the haemophilia on. It has not had the same impact on her life and therefore she has no idea of what I have been through and continue to go through.
53. The only person who has lived this with me is my husband [GRO-B]. He worries for me and we both fear that the virus will come back.

Section 6. Treatment/Care/Support

54. I have never been offered counselling or psychological support in relation to my HCV infection. I would have possibly accepted the support and it would have been nice to be asked.

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- 55. I was prescribed a four-week course of anti-anxiety medications but I left them in the cupboard and never took them.
- 56. I used to be part of a local HCV support group in [GRO-B] and I found that helpful, but it was an out of sight out of mind kind of thing and it focused on helping each other rather than receiving professional support.
- 57. I recently received a letter from EIBSS stating that I was entitled to £900 towards counselling and psychological support, but this was obviously introduced as a result of the ongoing Infected Blood Inquiry.

Section 7. Financial Assistance

- 58. I became aware of the Skipton Fund from either the Haemophilia Society or one of the haemophilia nurses and made an application in 2002. It was a fairly easy process and the medics endorsed my application. I received a Stage 1 Payment of £20,000.
- 59. I receive EIBSS special category measures payments as a result of complications which have arisen from the treatment – anxiety, illness and tiredness to name but three. They put out a regular payment of different levels, but I receive £28,000 annually along with a winter fuel allowance of £500. I also receive free prescriptions and the government through EIBSS will pay for my funeral.

Section 8. Other Issues

- 60. I feel that the contaminated blood scandal has been a complete cover up and the Inquiry has come too late for a lot of people. No amount of compensation will ever pay for someone's health but it can go a long way in easing the pressures caused by the HCV infection.
- 61. I received a phone call from Bradford Hospital earlier on in the year to see if I would be involved with helping to promote HCV screening. I agreed to help because the scheme may help those with or without any symptoms of the virus.

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62. My Uncle, **U** born **GRO-B** 1932 had severe haemophilia A and was diagnosed as a child. He had serious bleeds which required frequent administration of blood products and he even ended up in body casts. I remember that he could not bend his knees at all, as a result of bleeds in the knee joints.
63. I was very close with my Uncle. My parents split up when I was a teenager and he was my 'go to' for advice - he was my everything. He was a strange character in the sense that he always lived at home with my maternal grandmother and never had a relationship with anyone because of his haemophilia.
64. Uncle **U** passed away on **GRO-B** 1996 at the age of 64. The causes of his death were listed as: duodenal haemorrhage, duodenal ulcer and severe haemophilia A.
65. I only found out he was infected with HCV after he passed away – I had an appointment at Bradford Royal Infirmary for my own treatment and I asked the haematology department about my Uncle's medical records. One of the nurses remembered Uncle **U** and after some research, I was told that he had tested positive for HCV. I am not aware if he was tested for HIV and I have not seen his medical records.
66. This led me to making a posthumous application to the Skipton Fund on 11 December 2012. After some exchange of correspondence, I had to prove the beneficiaries of his estate because he had no will – to which I sent them a letter detailing the various family members who at that time had survived my Uncle. I cannot say that I ever had any problems with the application form.
67. Skipton made a Stage 1 payment to the beneficiaries of my uncle's estate and the sum was evenly split between the surviving members of the family.
68. As far as I am aware, he never knew that he had been infected with HCV – he never discussed it with me and considering how close we were, I think he would have done. I was not aware of him experiencing any symptoms related to the infection and I would not say that he suffered with jaundice. I do not recall him ever

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being extremely tired. I do not recall him being extremely tired but this is hard to say because he just wasn't a complainer and just got on with life.

69. I just wanted to add my uncle's case to my own. As I have stated, we didn't know about his HCV before he died and I doubt if he did but I wanted this to be recorded in some way within the Inquiry, on his behalf.

Statement of Truth

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

Signed

GRO-B

Dated

17/6/2021