

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN4358001

Exhibits: Nil

Dated:

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 30 June 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1968. I reside in GRO-B Northants. I am divorced, and have two children from the marriage, a daughter aged 33 and a son aged 25. I am a production manager for a GRO-B responsible for fitting and maintaining commercial vehicles.
2. I intend to speak about my infection with hepatitis C ('HCV'). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

Section 2. How Infected

3. I was born in [GRO-B] Essex. My family are of [GRO-B] and we moved to Ireland for several years when I was a child. In the early 1980s we moved back to England and settled in [GRO-B]
4. When I was aged 16 I went to live with my sister, who was living in [GRO-B] London, at the time. I got a job aged 17 as a dispatch rider and courier, delivering parcels and letters all over London. I had a few minor accidents in this role, but nothing major.
5. Then, aged 17, I was involved in a serious road traffic accident. I didn't walk away from this accident. I was taken to University College Hospital, where they initially tried to discharge me from A&E. Because of my protestations and being in agony, they kept me in overnight for observation. They insisted there was nothing seriously wrong with me.
6. I remained in agony all night and the next morning they took me for an ultrasound scan. The scan showed that I had ruptured my spleen. I was then asked to sign a form consenting to an operation and I was taken straight down to the theatre.
7. The operation involved cutting me down the middle to remove my spleen. After the operation, the surgeon said that I had a lot of internal bleeding and that I was lucky to be alive. I was given a blood transfusion, around 4 or 5 litres of blood, during the operation because I had lost so much blood internally. I remember waking up from the operation with a saline drip and a blood bag connected to me.
8. After the operation I went back to [GRO-B] to live with my parents and to recuperate from the shock and the treatment. I did not return to my job as a dispatch rider. I also have to take penicillin for the

ANONYMOUS

rest of my life because the spleen fights infections, so having it removed has weakened my immune system.

9. By the late 1990s and early 2000s I was working as a full-time professional production manager. I had started to use intravenous drugs occasionally. This initially started with me using speed when I was out drinking with friends, but I began to use heroin as a form of relaxant. I only used my own needles, and I bought these and the equipment every time I went to the chemist to ensure they were clean.
10. Sometime in the early 2000s I visited a drug clinic where they did routine hepatitis tests. I remember the nurse asking me if I wanted a test and I said that I didn't need to do that. I explained that I didn't share needles and never had done. The nurse insisted that I had the test, so she took a mouth swab. A week later she phoned me up and said that I had hepatitis C.
11. After my diagnosis, I was referred to Kettering Hospital under the care of Dr Das, who still looks after me now. I had regular blood tests taken at my appointments, and Dr Das told me that my viral load was absolutely sky high.

Section 3. Other Infections

12. I have not had any other infections as a result of receiving an infected blood transfusion during my operation at UCH.

Section 4. Consent

13. I remember signing a form in the ultrasound room to consent to my operation at UCH to remove my spleen. I was not told at any time that blood administered to me could be contaminated, it was just a consent form to the operation. On the day of the operation I was 17, and there was no one else with me when I consented to the operation.

ANONYMOUS

14. I believe that I should have been warned at the time that blood may be infected, as I believe they knew of the risk at that time. I don't know what I would have said there and then, but I still believe that I should have been warned of the potential risks of receiving a blood transfusion.
15. I consented to being tested for HCV at the drug clinic, and I consented to all the treatments I have received.

Section 5. Impact

16. In the intervening years between my operation and my diagnosis with HCV, I noticed a gradual deterioration in my health. I used to be young and vibrant but I became much slower and more weighed down. I was sluggish and often had brain fog. The brain fog was especially apparent to my family, and my wife described it as like I had an early onset of dementia.
17. I became less lively, and I was slower in my thinking and words. I remember before the accident I was running around and enjoying life. I used to play football but that stopped after the operation. I was sluggish in general and lethargic.
18. I can remember everything about being in UCH, signing the forms for my operation, waking up from the operation, the doctors and everything. I could even describe the ward in detail right now. Yet if my wife asked me what we did last week I could not remember. I was with my ex-wife for 28 years and she knew me better than anyone.
19. My eldest daughter especially witnessed a lot of my health problems. She says that my mind and memory was terrible and the brain fog was very evident to her. She called me lazy because she didn't understand HCV and the effects it had on me.

ANONYMOUS

20. My children used to call me 'Mr Grumpy'. I had mood swings and I was depressive, which was completely out of character.
21. The depression properly set in after my diagnosis with HCV and the subsequent stress and anxiety associated with the infection. I was argumentative; I would argue over anything, even what sandwich filling I had. I felt that nothing was ever good enough.
22. From my diagnosis with HCV in the late 1990s, I was treated by Dr Das at Kettering Hospital. By 2012, my wife had discovered a new triple therapy through her online research. We went to see a nurse at Kettering Hospital who said that a triple therapy for HCV did not exist and it certainly wasn't available in Northamptonshire. She told us not to believe everything you read online.
23. We then went to see Dr Das who said that it was a new treatment that could potentially be available to me. He said that it had a 75% chance of success. By this stage I was bloated, my skin was yellow and my eyes were jaundiced.
24. I had to work through all of this due to financial pressures but it was extremely difficult. I was constantly worried about work and finances. If I lost my job, we would have lost the house and been out on the street. It was a constant worry alongside my already, ill health.
25. As a result of this, I made sure that I went to work despite my deteriorating health. I remember one day bumping into a woman at work who I had not seen for a while. When she saw me she stopped in her tracks, put her hand over her mouth and said 'oh my god' in shock at my appearance. I didn't realise how bad I looked until that day. Despite this I strived to continue working.
26. In summer 2012, Dr Das applied for funding for me to start the triple therapy treatment. The funding application was accepted and he

ANONYMOUS

offered me the treatment soon after. I was told that it would last for up to a year. I cannot recall what medication the treatment consisted of.

27. From the very first day of starting the treatment I was severely ill. After taking the first injection whilst sat on the bed at home, my wife described me as looking like the exorcist. My back was bent backwards, I was sick and I had cramp. I remember having to buy olive oil to drink when taking the tablets. It was explained to me that I had to drink something with a high fat content when washing down one of the tablets. It had to be a certain quantity of fat taken with the tablet so it could process through the system.

28. Throughout the triple therapy treatment, I still went to work when I could. The financial pressures were immense, and I was worried all the time about losing my job. Thankfully the company I was working with were very supportive and understanding. They were flexible with my hours so that I could attend appointments. I am a conscientious person but I knew that I must have been frustrating for my boss because I was always asking for half days, or I would have to go home as I was being sick at work.

29. I stopped the triple therapy treatment in October 2012 after around 6 months. The hospital agreed with me that it was the right time to stop it. I couldn't eat or digest anything as I was sick straightaway. My family and friends said afterwards that they didn't expect me to see the New Year. I was still yellow and jaundiced, and they all thought I would die after the treatment. I said at the time that I wished I hadn't taken it.

30. After stopping the triple therapy treatment in October 2012, my viral load had gone down a bit. I then became really ill and my brain fog was noticeably worse. I was taken to Kettering Hospital in November and December 2012 where I was admitted to A&E.

31. On the second occasion I was admitted, in December 2012, Dr Das invited me to the family room with my family for a chat. He said that he

ANONYMOUS

had to refer me to the Queen Elizabeth Hospital in Birmingham to see a specialist liver doctor.

32. Dr Das explained that the chances were that I would now need a liver transplant. He said that it was so decompensated that it would not work. At the time I was so pessimistic about my chances, and I said 'what's the point?' I thought it was so unrealistic and said 'that isn't going to happen is it'. I thought the prospect of getting a suitable liver replacement was too far-fetched. My wife tried to be positive and said that we should try.
33. I was in Kettering Hospital over Christmas 2012. I was allowed home for Christmas dinner that afternoon but I was sick into the wheelie bin straight after eating. I recall having an ultrasound on my liver during this period, which showed scarring of the liver. The nurses said that I knew that already because I had HCV.
34. At my first appointment at Queen Elizabeth Hospital Birmingham they said they should do a scan on my liver. I said that there was no point as I had one at Kettering Hospital last week, but they explained that they do all their own tests and do not rely on other hospital's notes.
35. The scan at Queen Elizabeth Hospital Birmingham showed two cancerous tumours on my liver. They were 2 and 2.5 cm big, and I was told that if they grew to 3cm or I developed a third tumour then it would be inoperable. They then gave me 3 months to live.
36. Prior to this, I was already on the liver transplant list. Once the tumours had been found, however, they put me on the priority list. The hospital held a daily meeting with hepatologists and surgeons to discuss who should be on the list. I was never judged for my previous drug use, despite me being on methadone at the time.
37. Dr Alshakari at Queen Elizabeth Hospital Birmingham dealt with liver complications such as cancer and cirrhosis. When he told us about the

ANONYMOUS

tumours I asked why Kettering did not find this when they did the scan. He only said that they did their own work and were liver specialists.

38. Dr Alshakari told me that I had 3 months to live and that my quality of life would deteriorate rapidly. I asked about the option of any further treatment and he said no. He said the only option was for a complete organ transplant.

39. Dr Alshakari said that he could test my family to see if a match could be used as a part donation as their liver would grow back afterwards. Both my daughter and son were tested, and my daughter was deemed to be a suitable donor. They asked her questions such as if she was being pressurised into doing it and if someone was paying her to do it.

40. I eventually decided that she should not go through with it. I didn't want her to go through such a big operation and I was adamant that she wouldn't do it. Although she wanted to save me, I did not want her to have the operation. Ultimately, they said that I needed a full liver organ in me rather than a part transplant as a part-donation would not function well enough to keep me alive owing to the stage I was at.

41. I was on the transplant priority list for 6 days before being offered a new liver. I remember that it was Grand National day, on 06 April 2013. I had gone into town to put a bet on with my daughter when they phoned me telling me to get to Queen Elizabeth Hospital in Birmingham as they had a liver on the way up from Devon.

42. When I got to the hospital I was taken straight down into the theatre for the operation. I was extremely bloated and jaundiced. The operation was meant to last for 8 hours, but it took around 4 and a half hours. When I woke up my eyes and skin were no longer jaundiced whatsoever.

ANONYMOUS

43. As a result of having someone else's liver, I have to take anti-rejection drugs for the rest of my life. It took them a while to work out the best dosage of anti-rejection drugs. I take about 15 tablets a day.
44. The donor whose liver I have died in a car crash aged 21. Psychologically I am very aware that I have an alien object in my body, which causes me stress and anxiety. It is almost like a form of claustrophobia because it is always there and there is nothing I can do about it.
45. I eventually told my boss, who was the CEO of the company, that I had HCV after hearing that his wife also had hepatitis. I told him after my transplant and he said that I was to be paid in full while I was off. Apparently he left a note in my file saying that I was to be paid in full whenever I took a morning or afternoon off for appointments. In total, I was in hospital for 5 days after the operation and I was off work for 9 weeks.
46. The effects of the HCV and the treatment and liver transplant all had a cumulative effect on my marriage. It was a sexless marriage. This was the last thing on my mind. I did not even consider the implications of this for my wife, who was a healthy person, because of the effects of my illness. She had to put up with so much because of my illness and she dealt with everything for me. I would not be here now without her. She said that I needed a carer, and she was right. I have since apologised to her, and we still speak now despite separating around 4 years ago. I am forever grateful to her for all her help.
47. I informed my dentist that I had been diagnosed with HCV. After completing the form showing that I had HCV, the dentist would tell the assistant dental nurse to leave the room when he was treating me. I remember them asking about my medication at each appointment. Other than this, my dental treatment was largely unaffected.

ANONYMOUS

48. I lost all ambition to progress my career. I just lived from day to day. Had it not been for my infection with HCV, I believe that I would have gone a lot further in life. All my siblings are high achievers, yet I never progressed and did not go to university because of my illnesses. I had no structure after that. I would have gone to university had I not been infected. I often feel like the black sheep of the family.
49. My social life was effectively non-existent throughout the entirety of this. I couldn't go anywhere, and frankly I didn't want to go anywhere. I lost all enthusiasm and drive, and I secluded myself from society.
50. My intravenous drug use lasted for a few years, but I was fully functioning and working whilst using. I was extremely careful with the equipment that I used, and I also bought sterilised needles from the chemist. I never went to a drug den or back alleys.
51. I went on methadone and did not touch drugs ever again. I began to decrease my dosage on my own initiative. I eventually stopped using methadone and was completely clean. Prior to my liver transplant I had regular drug tests as they did not want to waste public money on someone who was still using drugs.
52. I witnessed and experienced a lot of stigma because of my infection with HCV. My colleagues at work who knew about my infection thought they could catch it off me just by being around me. They would not use cups or cutlery that I had used in the canteen. On reflection, they did not know anything about HCV and how it is contracted. They all thought that it was caused by alcohol.
53. When I went for a blood test, I remember the nurse seeing HCV on my form and putting gloves on in a deliberate manner. I certainly felt that I was treated differently.
54. Throughout this entire ordeal, my daughter recalls that it was like her having to witness me dying in front of her eyes every day. My family

ANONYMOUS

were planning on the assumption that I wouldn't make it. If I could have seen myself I probably would have thought the same.

55. My life is now controlled by the strict regime of my anti-rejection drugs. It is a constant concern as I don't want to put any undue pressure on my liver. I take blood thinners daily as I have blood clotting issues in my legs. I have to wear flight socks if I am flying abroad. I had two operations in my legs for a deep vein thrombosis. I believe that the HCV was responsible for this. I feel the cold a lot and my blood circulation is generally poor. My hands go blue very easily.

56. I am unable to get insurance and a mortgage. I need full medical insurance just for a trip to Ireland. I have had to see a broker to get this.

57. Although I have to live with the fact that the liver could reject at any time, I have chosen not to live my life in fear.

Section 6. Treatment/Care/Support

58. I was offered counselling by my employer around 3 years ago. I had been told by my GP that they did not have the resources for people with 'mild' depression and I was not offered counselling.

59. The mental health awareness team at my employer referred me for counselling. I had a block of 6 sessions which were 1 hour each. The counsellor had no real medical qualifications, it was more of an opportunity to talk to someone.

Section 7. Financial Assistance

60. Dr Mutimer, of the queen Elizabeth hospital in Birmingham told me about the Skipton Fund. He said it was most probable that I contracted HCV from contaminated blood during my operation in 1986. He did tell

ANONYMOUS

me that this was difficult to prove, and that I would be rejected anyway because of my previous intravenous drug use. Dr Mutimer still encouraged me to apply.

61. My application to the Skipton Fund was rejected on the basis of my previous intravenous drug use. My application was supported by a letter from Dr Mutimer and my medical records from UCH. The medical records did not however confirm that I had a blood transfusion.
62. I appealed against the original decision and again sent the paperwork I received from UCH. This appeal was rejected on the same basis. The letter I received in response said that it was 'more probable' that the intravenous drug use was the cause of my HCV infection. I strongly dispute this owing to the hygienic precautions I took when I used drugs intravenously.
63. I was particularly frustrated by the appeal process, which was all in writing. I wanted to outline my case and put my point across in person, but this was not possible. It felt like another hurdle in a long life of setbacks.
64. I was pessimistic anyway when applying to the Skipton Fund, and I was certainly not surprised that I was rejected. The process frustrated me enormously as I feel that they judged me straight away once they read about my previous intravenous drug use. I felt like they labelled me as a drug addict. I had explained my limited use of drugs and the precautions I took when using drugs, but this was apparently ignored.
65. The appeal process disappointed me greatly. I wanted the opportunity to speak to the appeal panel and make my case. I suspect that they didn't have the resources available to hold appeal hearings in person. It felt like a job interview doing the letter and there was a distinct lack of personal understanding.

Section 8. Other Issues

ANONYMOUS

66. I have had a long list of setbacks ever since my operation in 1986. All the different stages of my life have been affected by my HCV and the treatment. I am 51 now, and I had just turned 18 when this started. It has affected a huge part of my life.

67. I haven't enjoyed a normal life at any time of my life. I assume that as I get older things will probably get worse. My life is completely dictated by medical appointments and medical conditions. Although I have to live in the knowledge that my new liver could reject at any time, I do not live in fear.

Statement of Truth

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

Signed GRO-B _____

Dated 31/10/20