

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0007001

Exhibits: WITN0007002-11

Dated: 25-01-2021

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 the 22 January 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1980 and my address is known to the Inquiry. I am currently unemployed. I am happily married and have two children.
2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I contracted as a result of being given contaminated blood products to treat haemophilia.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life and that of my family.

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. My brother [GRO-B: B] and I both have a haemophilia disorder. He is also infected with HCV. My youngest sibling is a carrier of haemophilia.
6. I was diagnosed with haemophilia A at 2 years old and started factor treatment around 3-4 years old.
7. As a child I had regular infusions of concentrate and spent a lot of time in the Royal Victoria Hospital in Belfast. Being one of six children meant there was a lot of rough and tumble growing up.
8. Dealing with haemophilia as a child made it difficult at school. Teachers would overreact about a bleed, children would not involve you in activities, and I was labelled a bleeder.
9. I suffered with particularly bad nosebleeds and in 1991 I was blue lighted from [GRO-B] to hospital in Belfast after using up two boxes of tissues on one episode. It was so serious that I required a blood transfusion, and this is the only occasion I recall having one. Sometime after this, I did have a major bleed that burst through my shin but I am sure I did not receive a blood transfusion at that time.
10. There was a lot of medical interest in my blood during my early years. The haematology centre would arrange frequent appointments to take blood. I think it was because I was such a young subject. I lived in [GRO-B] at the time and had to travel all the way to Belfast. There was no financial help for my parents, and my siblings would have to be looked after by others whilst they accompanied me. It created a lot of conflict within the family.

ANONYMOUS

11. At some stage, between 1996 and 1997 the Royal Victoria Hospital, took the decision to move the whole adult Haematology Department out of the main building and into a portacabin. They wanted us out of the way, or so it seemed and it felt very isolating.
12. Over the years my severity of haemophilia has changed, from severe to moderate. I had a bleeding disorder information card that stated I had severe haemophilia A. The consultant tried to take it off me before I was given another card stating only haemophilia A. This is a concern and I would like to know why it has changed. **(See Exhibit WITN0007002)**
13. According to medical notes, the first admission from the NHS that I had HCV was in 1992 **(See Exhibit WITN0007003)**. I was not told at this point nor were my parents. Why were they not informed? However, interestingly, liver function tests were taken regularly prior to 1992. **(See Exhibit WITN0007004)** I would like to know the real reason why. I was lucky to find the notes and it took several calls and pleading for checks to be made before they were found in an outside storage area in the City hospital. They were labelled under oncology/cancer and I wonder what would have happened to them had I not made the request.
14. The infection was not mentioned until it was brought up in 1995. I was 15 at the time and weighed only 8 stone. My parents were summoned to the hospital and given the news that I had tested positive for HCV. They were advised not to tell me about it and I have this in writing. **(See Exhibit WITN0007005)** Dr Dempsey was the haematologist at the time who spoke to them. They were told not to worry too much and that it was just a little bug in my blood.
15. My mother has little memory of what exactly they were told as it was a relatively new disease. She did not know how to deal with the diagnosis so contacted the Haemophilia Society for support, but they could offer little help.

ANONYMOUS

16. At this age I had an interest in current affairs and felt grown up. I was capable enough to handle and process the diagnosis, but the medical professionals were of the opinion that I did not have the right to know.
17. My parents informed me I had been infected with HCV when I was around 16. They were not in a position to give me information on how to manage and deal with the virus as they themselves had received little knowledge or assistance from the medical authorities.
18. I have no indication of when I received the infected product or how and cannot find anything in my medical notes that pinpoints the time. I would like to know when I was infected. I have used Factor products since the early 1980s and there is a record of me receiving Factor V111 in both March and October of 1991. **(See Exhibit WITN0007006)**
19. Dr Main was the haematologist I saw as a young adult, but I now have Gary Benson. He has been my haematologist for at least a decade.

Section 3. Other Infections

20. I have not received any infection other than HCV as a result of being given infected blood products.
21. I have medical records that prove that I have been regularly tested for HIV and these have been negative.
22. I received a general letter in 2004 stating that as a Haemophiliac I may be at risk from Factor product contaminated with vCJD. **(See Exhibit WITN0007007)** I went on to complete a form to say I did not want to know whether I had vCJD. There is no cure and once the disease starts to surface there is no hope. I believe the letter was part of a lookback exercise.

Section 4. Consent

23. Even though I was 15 years of age I was never made aware that my blood was being tested for HCV. It is possible that my parents had consented on my behalf. However, I feel strongly that at that age I should have had the right to be told what the problem may be.
24. I felt that I had been treated as a *lab rat* after I read through my medical records. I volunteered to be tested for haemophilia research in London because they could not get enough participants, yet at the time I was unaware I was being used for research purposes in relation to HCV anyway. To me that seems the most likely explanation as to why details of my infection were not given to my family and I when it was initially discovered.
25. My wife was not informed that they were testing her for HCV in 2011. She has tested negative for the virus.

Section 5. Impact

26. I felt dirty when I found out about the infection. I was brushed aside and it was always the elephant in the room at the haematology centre.
27. For obvious reasons, I did not take much treatment in the way of Factor products after the diagnosis. At times when I had a joint-bleed I would just leave it. The bleed seemed the safer alternative.
28. I did not feel unwell because of the HCV initially; I only had pain because of the haemophilia.
29. However, I did develop severe OCD and anxiety as a result of the infection with HCV. I became very conscious about cleanliness and would use Dettol on everything I touched. Whilst infected I would shower up to 4 times a day on average. I became completely obsessed with cleanliness.

ANONYMOUS

30. It does not do me any good to look at my medical records as it makes me physically sick. I find it very difficult to deal with the way I have been treated in some cases over the years.
31. I started a 9-month course of interferon and ribavirin to clear the virus in April 2000. The interferon was injected and the ribavirin was in tablet form. **(See Exhibit WITN0007008)** It was at the tail end of the treatment that I met my wife – the only good thing that happened to me during that period.
32. The treatment was horrendous and the only side effect I did not experience was hair loss. I lost a stone and a half in weight. I suffered from terrible nausea, insomnia and night sweats and noticed an enhanced level of joint pain particularly in the extremities, my hands and feet. The level of tiredness was debilitating and I found it hard to do the basics. I also experienced mood swings that did not make me a pleasant person to be around. My appetite went and I was surviving on meal replacement shakes. Having gone through all that, the treatment was not successful. I found out for myself in early 2001, Dr McNulty, who had been overseeing my treatment did not tell me straight away. I despaired that I would never be free of the virus.
33. The second course of combined treatment, interferon and ribavirin again, started in August 2005. **(See Exhibit WITN0007009)** This time it was 48 weeks and consisted of tablets and injections into the stomach. I had to take a 3-4 week break from taking the medication as I became so ill. I lost so much weight and thought continuing would kill me. I had no appetite, was constantly sick, and suffered with extreme fatigue as before. The hospital was receiving positive indications that my body was fighting the virus, but I could not continue. I felt like curling up and dying and I would have gone through with that at that time if I could have, it was so bad.

ANONYMOUS

34. It took a long time before I had an appointment with a dietician whilst on the course of mediation despite my weight loss and the fact I had experienced this symptom in the past.
35. Part of the treatment consisted of taking antidepressants for the mood swings and feelings of being so 'down'. However, I weaned myself off them without the doctors knowing. I wanted the treatment to make me better, but the antidepressants were affecting my whole personality. I am used to not being in control of my body, but it is different when it is your mind.
36. After resuming the treatment, the viral load cleared and in July 2006 I was confirmed as negative for the virus. **(See Exhibit WITN0007010)**. I have been told that it will not come back but I am unsure if the virus can be completely eradicated and I live with the constant fear that it may return.
37. The treatment has left scars, and to this day my hands and feet are still affected. At times it feels as though my legs have been run over by a steamroller. I recently had neurological tests but they were not ordered for some time despite my complaints to doctors. Consultant Gary Benson, the haematologist explained that it was not a common side affect with the HCV and in fact the Rheumatology Department has now signed me off.
38. I still suffer with fatigue and regular bouts of joint pain even though I have cleared the virus.
39. Even after the successful course of treatment I still did not think that I would live very long or reach an old age. I have always seen the infection as a death sentence hanging over my head. I therefore drank quite heavily and felt I should live life hard and party. I did not care about the consequences, as I never thought I would make it to 30.
40. I have never had a liver biopsy, until recently when I had a fibro-scan and was consistently told it is too dangerous for haemophiliacs. I knew it could be done and have had successful hernia operations in the past, so found

ANONYMOUS

the refusal of a biopsy concerning. Did they not want to know the extent of the liver damage until it was too late? I find it all rather sinister that I have had the infection from childhood, but a biopsy has not been taken at any stage. I was aware that there were other methods but until now a scan of the liver had not been offered either.

41. I have only seen Dr Callender, the liver specialist once. He was known as Dr Death amongst the Haemophilia patients as we always suspected he was aware of the dangers of Hepatitis C.
42. I used to be seen every 3 months to have a blood test, but this has been reduced to every 6 months.
43. I have a hiatus hernia that went undiagnosed for years. After complaining of persisting stomach problems, I happened to be seen by a junior doctor during a training round. He found the hernia within seconds, yet three different GPs at my old practice had examined me previously without spotting it. A camera confirmed the hernia. I believe the amount of vomiting I suffered during the HCV treatments caused the hernia.
44. My current GP picked up on the fact that I had been on co-codamol for a number of years, so I was put on a programme to come off the medication. It took over a year. I did not notice I was addicted to them but they had become part of my life. The withdrawal was painful and took time but I could never go back to taking co-codamol tablets again.
45. I have seen the effects of morphine; I have never taken it for pain relief myself. I am all too aware of the damage it has caused to others including people close to me.
46. In regard to dental care, the haematology centre had a dental part attached but we were later referred to the school of dentistry at the Royal Victoria. I kept receiving notice that I had been missing appointments, but I had not booked any. They had a policy of "three strikes and you're out". I believe

ANONYMOUS

that the missed appointments were deliberately manipulated to prevent me being treated. I was taken off the books and lost at least 7 years of dentistry.

47. I am now successfully registered with a local dentist. I would like to say that on my final appointment at the school of dentistry I recall that all of the tools were disposable and everything was bagged up for destruction after I was seen. Whilst understanding the need for precautions, it makes you feel horrible being treated so differently.
48. I do not declare HCV on travel insurance forms, as I would be uninsurable. It is hard enough to find insurance as a haemophiliac. I take factor products and my EHIC card for travel in Europe, and always have the address of a nearby haemophilia centre. I have no aspirations to travel further afield although my wife does.
49. I now regularly experience anxiety within crowds of people, which leads to sweats, disorientation and breathing issues. I find it embarrassing. The anxiety I suffer from I believe stems from my infection with HCV, the medication prescribed to treat it and the emotional trauma the whole experience generates for you, your family and friends.
50. Our family was very close so only a select few people were aware of the HCV infection. There are still aunts and uncles of mine that do not know about B and I. If I had told people I was HCV positive I would have been blacklisted in the community. A lot of people remain ignorant of the circumstances surrounding the virus. All too often it is associated with drug use.
51. There was a stigma with haemophilia alone, without mentioning HCV as well. I kept quiet about the infection initially with my then to be wife. It would not have been the best way to introduce myself.
52. My education was ruined by the infection. I was a clever capable boy, but I did not see the point in gaining an education and stressing over exams

ANONYMOUS

when I expected not to recover. Ironically I was interested in pursuing medicine.

53. I took a leisure course at college but could not finish because of treatment for HCV. I was also unable to finish a bar managers course for the same reason.
54. I did work in a bar up until 10 years ago, when I had to stop working to look after my wife. She was diagnosed with Antiphospholipid Syndrome, a clotting disorder. My wife's health issues have also affected our lives.
55. I feel guilty about my wife's health conditions as they spontaneously arose. My brother's partner also ended up developing blood clots. I feel as though I have infected my wife in some capacity, either by the HCV or through the treatment. Doctors have confirmed that I have not, but in my head I feel responsible. I wonder if the stress of dealing with my condition and the problems I experienced with treatment contributed to her poor health. I hate the word coincidence, and every time I ask a question I wonder if I receive an honest answer.
56. My grandfather was also given contaminated blood products and died as a result. I am unsure whether he was infected with HCV or HIV. The scandal has affected a number of generations in my family.
57. I had a fall out with my parents over the fact that I was not told of the infection straight away. They should have passed on the diagnosis as soon as they were informed. I cannot believe they withheld such information from a mature 15 year old. Equally, I find it scandalous that a medical professional would tell them to do so.
58. I remember my brother saying that on one occasion he visited his sister in law and her children, and she remarked 'do you mind if I clean these toys after you have touched them'. Still to this day I am worried about what I touch and about how I prepare food.

59. I do handle my children's food but I am cautious all the time and when they were babies I would wear rubber gloves to change their nappies. I cannot help it but I have pushed the extreme cleanliness onto them.

Section 6. Treatment/Care/Support

60. I have never had any treatment refused.
61. I have correspondence between my GP and consultant at the Royal Victoria Hospital stating treatments were available but they were not viable because of the expense and low success rate. **(See Exhibit WITN0007011)** Personally, I would have rather taken the lower result chance in exchange for the possibility of an earlier cure.
62. I am aware of correspondence where the hospital begged my GP practice to pay for the treatment, even though they caused the infection in the first place.
63. At one point I went to see a skin specialist in Belfast because I had lesions on my legs. These were in fact another side effect of my treatment. During the appointment 14 student medics came in. I was not asked if they could observe, the consultant merely said *hope you do not mind, as this is a training hospital*. I was only showing my legs but it was one of the most embarrassing appointments I have had in my life. It was particularly hard as the students were the same age as me.
64. A number of years ago I was offered psychological support. I can't remember the context. There is no evidence in my medical records but I recall there was something offered. I did not take it up at that time and it certainly did not relate to my initial diagnosis. There was no support at that time.

65. Currently I am seeing a psychologist. That has been the case for the past year, possibly longer but not much more. Currently, the sessions are virtual and they are proving of benefit to me.

Section 7. Financial Assistance

66. I became aware of the Skipton Fund in 2001 through the haematology centre.
67. I applied directly but much of the application process was done on my behalf. I would have only signed the paperwork.
68. A one off payment of £20,000 was granted for being infected with HCV through contaminated blood products. Conditions were attached to the payment and I had to sign a disclaimer prohibiting further entitlement and waiving liability against the health service.
69. The haematology centre instructed me to accept the payment because I might not be entitled to anything else and at that point I thought I was not going to live long anyway.
70. I was advised I could only apply to the Skipton Fund and because of signing the disclaimer I felt I could not approach other organisations.
71. Later, I did receive an additional £5000 from another fund but I cannot recall their name or how it came about.
72. In the past I received £340.33 a month from the Belfast Health Organisation (BHO). It has now increased to £1546.33 since April this year on a par with England.
73. There was no paperwork supplied with the monthly money. I had to phone them up to ask who exactly they were. The money just arrived in my bank

ANONYMOUS

account without explanation. I am talking here about the initial payment of £340.33 when it started.

74. The amount of compensation I did received was low. I am not money orientated but I would have received more from a car accident, where my whole life would not have been affected. I feel that the payments do not reflect the degree of suffering that I, and my wife and family in particular, have experienced due to the mistake made by the NHS.
75. Of late, I was unsuccessful in relation to a mandatory reconsideration of my PIP decision. I went to a courthouse for the tribunal. I have never been in a courthouse in my life and it is in the centre of our town, so people notice who goes in and out. It was an embarrassing experience and I was more or less advised not to come back again.
76. Beforehand, I received DLA payments and HCV was never mentioned. It would have been my parents who completed the form and I was assured it would carry on for life.

Section 8. Other Issues

77. I contacted my local MP GRO-B a number of years before the Inquiry was announced. She agreed to bring up my story in Parliament. I went to the haematologist at the Royal Victoria Hospital to ask when I was first infected and how, in order to add this information to the story but I am still waiting on a reply. I want to get my story out and have these questions dealt with.
78. I think the contaminated blood scandal is still buried and to this day the NHS is not transparent.
79. On one occasion I went to St Thomas' Hospital in London for a bleed in my arm. An ultrasound was taken to discover where exactly the bleed was coming from, and I saw a physiotherapist straight away. I went back to Gary

ANONYMOUS

Benson to ask what the local trust was doing with their money and why did we not have similar advanced technology in Northern Ireland. He replied that we do not get the best treatment. A couple of months later we had the same ultrasound machines. There needs to be consistent treatment and care throughout the UK.

80. The statistics leave me very nervous as a lot of people are dying from liver cancer resulting from HCV and the failure to detect and treat it early enough. Also, there are those who don't survive the side effects of the interferon treatment. Perhaps those who knew about and condoned the use of infected blood thought there would not be too many voices left in future years to raise complaint.
81. My treatment at the hands of the NHS has left with a deep mistrust of doctors and the system. I will always question what they say and why. My paranoia will itself require treatment and so the legacy of the infected product continues with the burden falling on the organisation that was responsible for the initial failure.
82. When I spoke to Dr Gary Benson regarding obtaining my medical notes, he asked if I had received 'the middle volume.' It appears that the doctors had kept this volume separately to the rest of my notes and I believe it would be relevant to my statement and the Inquiry. I would like to obtain a copy of this 'middle volume' and have requested it, although I am still waiting.

Statement of Truth

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

Signe

GRO-B

Dated 25-01-2021