

ANONYMOUS

Witness Name: GRO-B ANON

Statement No.: WITN4356001

Exhibits: Nil

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 August 2020 .

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1959 and I live alone in GRO-B I am currently unemployed, though I am a GRO-B in the GRO-B sector. I am also a keen musician, singer songwriter and artist.
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 and my family.

Section 2. How Infected

3. I was born in GRO-B and grew up there with my family. As a child I was a really good swimmer. I used to go to the local baths a lot. Around age 11 I began to develop a pain in my left ear. This was originally diagnosed as an ear infection.
4. GRO-B did not have an ear nose and throat department at that time, so I was referred to Tynemouth and Newcastle to see ear specialists. I had an operation aged 12 but this didn't work. I still had the infection after the operation.
5. For around 3 or 4 years my Mum took me to see specialists all over the region, but the ear pain persisted and nothing was done about it. I was given antibiotics but these did not work either.
6. After this time, I became sick from the constant prodding and poking in my ear by health professionals. I used to use a steel pick with cotton wool on the end to try and clean my ear. The ear was scarred by a locum trainee doctor which caused me a great amount of pain and aggravation. After this incident I refused to see any more doctors, and by age 16 I learnt to live with it. By this time, I did not experience a lot of pain in the ear, but it did discharge.
7. When I was aged 25, I went to see my GP. He immediately referred me to GRO-B Hospital in GRO-B. I was seen by Dr GRO-B an Ear Nose and Throat specialist who ran the clinic in GRO-B. Dr GRO-B operated on my ear by performing a modified radical mastoidectomy. This operation lasted for around 3 to 4 hours and involved my middle ear being reconstructed.
8. This was the first time that this type of operation had been performed. It was quite radical at that time, and involved the middle ear being completely destroyed. Dr GRO-B then had to cut away the

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mastoid bone and reconstructed the ear drum with grafts used from membrane of the ear. I recall being in the hospital for around 2 weeks, and it was a big operation at the time. I have since found all my medical notes from [GRO-B] Hospital, but there is no record of me having had an operation, nor being under Dr [GRO-B] s care.

9. My ear was bleeding for several days after the operation. I remember waking up and lying on a pillow saturated in blood. I was put on my left side so the blood would draw out of my left ear. It slowly began to dry up and the bleeding eventually stopped. On reflection, I believe that I may have received a blood transfusion during the operation, though I am unable to confirm this as I was under anaesthetic. I have no recollection of receiving blood after the operation. Dr [GRO-B] did not indicate to me that I had received blood. He said that he had saved my life, as if the ear condition had carried on any longer it would have killed me.
10. I saw the operation as a complete success. I no longer suffered with pain in my ear, and the ear was no longer discharging. It did however cause some unrepairable damage, and I slowly began to lose my hearing. I am now completely deaf in my left ear.
11. I went to the hospital at least once a year to get my ear cleaned. This continued for a few years after the operation but the appointments gradually petered out. It was meant to carry on for the rest of my life but I received no further contact. I was working in [GRO-B] for 3 to 4 years and my ear was fine, and I heard nothing more from the hospital.
12. Between 1992 and 1994, I went for a regular check-up where I received a blood test. I was told the results of the tests, which found that I had chronic hepatitis C, genotype 1A. I was referred to Professor Margaret Bassendine at the Freeman Hospital soon after my diagnosis.
13. At the first appointment with Professor Bassendine I was given information about the risk of transmitting HCV to others. This was all

explained to me by the nurses at the Freeman Hospital. They asked me questions about how I could have contracted the HCV. I said I have a tattoo, and that I had an operation in 1985. I remember thinking that I would never have known about my infection had I not been for the routine check-up. I recall being told that there was nothing in the way of treatments for HCV back then.

14. By 1998 or 1999, Professor Bassendine said that I could have received a blood transfusion during my operation. Around this time I was offered interferon treatment. The course of treatment was due to last for around 9 months. Professor Bassendine warned me that it would be heavy-going and it was a heavy load. Having agreed to undergo the treatment, I was given injections weekly but it was ultimately unsuccessful in clearing the HCV. It was certainly an experimental treatment as they did not have anything else to treat the infection back then.
15. For the next 20 years or so nothing was done to treat my HCV. I would go to see Professor Bassendine regularly and they would take blood tests. I was not offered any form of treatment for around 20 years, all they did was take blood tests.
16. Occasionally I had an ultrasound on my liver. I was told that my liver was alright, that there was a bit of fatty tissue but this was nothing to worry about. I don't drink alcohol at all, and have not drunk for over 20 years. These periodic ultrasounds of my liver did not show anything of concern. I was offered a liver biopsy but I declined. I did not want this, and from the ultrasounds report my liver was alright.
17. Out of the blue, in January 2020, I was offered a new treatment for my HCV. This treatment did not involve any injections, and I took tablets daily for the 3-month course. This treatment ended in March 2020, and since then I have had no contact with the hospital and I do not know the results of the treatment. This was all stopped during the coronavirus outbreak. I had blood tests at the Freeman Hospital 2

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weeks ago, and I am still awaiting the results to see if the treatment has worked in clearing the HCV.

Section 3. Other Infections

18. I do not believe that I have contracted any other infections apart from HCV.

Section 4. Consent

19. I consented to all my treatments, both for my ear and for HCV.

20. I believe that some of the treatments have been experimental. The interferon treatment was experimental and I believe that the treatment I had this year was experimental. They pioneered the HCV treatments but I still believe they are experimental. I consented to participating in all the experimental treatments, and consented to all tests undertaken. I wouldn't say that I was a guinea pig but they were learning and experimenting with good intentions.

Section 5. Impact

21. Before the treatment, I was fit, healthy and working. Ever since my diagnosis, my life has stopped for one reason or another. I have not been able to function properly, and I have suffered with severe mental health problems. I am no longer fit, active and healthy as I used to be, and I believe HCV has probably played a part in that. It is a blood disorder and it makes up a large part of my body, so of course it must have had an effect.

22. The first course of treatment in 1998/1999 had a significant impact on my mental health. Professor Bassendine warned me about depression prior to starting the course, and I was sent to a mental health assessment team. I had depression prior to starting the treatment, at which time I was aged approximately 32 years. The interferon treatment significantly worsened my mental health and I suffered from severe depression throughout the course of treatment.

23. The interferon treatment was heavy going from the very start. I experienced extreme fatigue and tiredness. I completely lost my appetite, barely eating at all, and my stomach shrank as a result. I felt nauseous and was frequently sick.

24. After completing 6 months of the course, I told the hospital that I was not eating much. I eventually stopped the treatment after 7 or 8 months because of my loss of appetite and the hospital's concerns at my weight loss. It took me at least 2 years to recover from the weight loss.

25. My mental health deteriorated rapidly after the treatment. I was in regular touch with mental health teams, and was referred to a psychiatrist. I had a mental breakdown, and the depression lasted a long time. I lost my job as a result of this and was unable to work. My social life was also detrimentally affected, and I lost all form of social interactions with my friends. There is a big gap between my 30s and now where I was depressed and incapacitated.

26. I did not feel able to discuss my infection with HCV with anyone except my mum and my brother. Even once I told them, they gave me a wide berth and there was always a degree of caution. I still saw them and spoke to them, but I believe they did not fully understand what it was and they were cautious around me as a result. The stigma associated with HCV is prevalent even now as it was synonymous with HIV/AIDS. I felt like a leper.

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27. I have never been married and I don't have any children. My social life and mental health suffered as a result of the HCV infection. I am quite isolated and lonely, as effectively, I isolated myself. I withdrew myself from general life. I thought that I had given it my best shot and just gave in. I shut the door from everyone as the depression kicked in.
28. More recently, I have met a girlfriend and have started to open the door again. I realise now that I have missed out on so much of my 30s, 40s and 50s, which are the vital years. I lost them all, and I believe HCV was at least partially to blame for this.
29. Not being able to work has affected me financially. I have not worked for over 20 years as a result of depression. I was once a skilled tradesman in construction and building, but I was unable to work for such a long and key period of my life. I am now on employment support allowance.
30. I don't fully know the effects of having chronic hepatitis C. I believe that it was a cause of my mental health problems, and could be a contributory factor in my current health problems. I was diagnosed with prostate cancer around 18 months ago, though there is no indication that this could be attributable to my infection with HCV. I was also diagnosed with emphysema 2 years ago. I used to smoke cigarettes but not heavily, and I do not know if HCV was a contributory factor or not.
31. I have suffered with kidney stones around 3 or 4 months ago. I went to A&E and was treated by opening the tubes up and dissolving the stones. I had a CT scan that showed everything is fine as I passed it out through my water. I have also had sciatica for about 10 years and arthritis for about 6 years. Again, I am unable to say whether HCV was a factor in these health conditions.

32. Over the last 10 years I have lost a lot of my teeth. They have just been dropping out, and I believe that HCV could be the cause. I did not have any infections or abscesses, and I now have just 2 teeth left.
33. To this day I do not know the cause of my infection with HCV. I was not promiscuous, have never injected drugs and there was no obvious and apparent reason why I would become infected with HCV. I was a clean-living person in that sense, so I believe the only explanation is a blood transfusion during my operation in 1985.

Section 6. Treatment/Care/Support

34. During my early 30s I was referred to the local mental health team. At the initial assessment I was diagnosed with borderline personality disorder. I believe that they used my diagnosis with borderline personality disorder as an excuse not to treat me, since they did not categorise this condition as a mental health problem.
35. As a result, I was not prescribed any medication at this time. This was a desperate, desolate period of my life. I felt like a bad person because of the stigma associated with borderline personality disorder. Eventually, my GP prescribed me antidepressants, which were effective to a certain extent.
36. My psychiatrist at the time referred me to the GRO-B Hospital in Croydon for a further assessment. I questioned this at first and asked if there was anything available nearby. I eventually agreed and travelled all the way to the GRO-B Hospital, only to be told that they would not accept me. The doctor said that they didn't accept people who were already on prescribed medication, which I was at that time.
37. The psychiatrist who referred me said that he was not aware that my GP had prescribed me antidepressants. I found this very hard to believe, since it would be common practice for the GP to liaise with the

psychiatrist about my treatment. I was very annoyed at being sent all the way to the GRO-B Hospital without my psychiatrist checking the criteria for my admission. I fell out with the psychiatrist and said that I didn't want anything more to do with the psychology teams.

38. I never went back and was incredibly angry at this incident. I made a complaint to the community care council but nothing came of it. This was a terrible period for me.

Section 7. Financial Assistance

39. Professor Bassendine advised me to apply to the Skipton Fund. She told me that I may have contracted hepatitis C through the operation I had in 1985. I had never heard of the Skipton Fund, so she gave me the address to contact them.

40. I did everything myself in applying to the fund. I spoke to my GP, Dr GRO-B who supported me in my efforts to find out what happened. I applied to the GRO-B Hospital for my medical records. I was able to access my GP records but the GRO-B Hospital wrote to me apologising and saying that they should have kept my medical records. They said that they had lost the records in the process of moving hospital sites and should have kept them.

41. My application to the Skipton Fund was rejected on the basis that they needed the hospital notes evidencing that I had a blood transfusion. They said I needed proof by way of physical notes confirming that I had a blood transfusion. I sent them my hospital letter saying that they had lost my medical records, but they still maintained that they needed proof.

42. Both my GP and I tried in writing to get the records. The GRO-B Hospital just apologised and said they were lost when they moved hospitals.

43. I appealed against this decision and attached the letter from the Freeman Hospital apologising for losing my records. This appeal was rejected by the Skipton Fund on the same basis, that I needed proof in the form of medical records showing that I had a blood transfusion. After this final rejection I just accepted the decision and gave up trying.

44. I have had no further financial assistance. I am on employment support allowance. I was not aware of the English Infected Blood Support Scheme ('EIBSS') until told about it by the Inquiry investigator. I have had no form of contact from anyone advising me of the existence of the EIBSS.

Section 8. Other Issues

45. I was not aware of the Infected Blood Inquiry. I only became aware of the Inquiry when I was contacted by the Inquiry investigator.

46. I am providing a statement to the Inquiry on a personal note. My involvement is based on the need to find out what happened to me. I would like the Inquiry to help me in directing me towards the truth of what happened and the facts. I want evidence proving that I had a blood transfusion, and I have no other motive.

47. I believe that it is suspicious that they did not find my medical records. I wondered how many others out there had been treated like me. I knew about contaminated blood products in the 1980s but said nothing about it. They have taken too long to finally get to the bottom of what happened.

Statement of Truth

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

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Signed

GRO-B

Dated

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