

ANONYMOUS

Anonymous

Witness Name: GRO-B

Statement No: WITN6046001

Exhibits: Nil

Dated: 16 December 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 06 December 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1979. I reside at GRO-B GRO-B live with my parents, and I have one younger sister. I currently work as a freelance illustrator.
2. I intend to speak about my infection with Hepatitis C ("HCV") having received one or all of the following; a blood transfusion and on numerous occasions, Cryoprecipitate and Factor VIII as treatment for haemophilia A from the age of three years old. In particular, I wish to discuss the nature of how I had learnt about my infection, how my illness had affected me, my family and the financial assistance I have received.

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3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I wish to be anonymous, as throughout my life, I have largely kept my HCV diagnosis to myself. There are only a handful of people who know about my HCV infection.
4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism and know my identity.
5. I wish to acknowledge that as I was only around six years old when I was diagnosed with HCV, I do not have many direct memories of that period. Instead, I have been able to provide approximate timeframes for matters based on life events, and information which has been passed on through my parents. However, these timeframes should be accepted as 'near to' rather than precise dates.
6. I have constructed this statement without access to my medical records.

Section 2. How Infected

7. When I was aged between two and three years old, I experienced a fall in the home which resulted in me having suffered a heavy bleed in my mouth. My parents immediately took me to Barnsley General Hospital ("Barnsley General"), to seek medical assistance.
8. As soon as I arrived at Barnsley General, the doctors in charge of my care were confused as to the cause of my bleeding. They also did not know whether this was an issue for a hospital, or a dental setting. Regardless, they patched me up, and I was discharged home that same day for a period of bed rest.
9. However, the next morning, I was awoken by my parents who had seen that that my whole mattress was soaked through with blood. My parents immediately took me to our dentist to seek medical assistance. They were told

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that my condition was so serious that I needed to go to hospital. I was taken to Barnsley General.

10. When my parents and I reached Barnsley General, due to the amount of blood I had lost, I was given an emergency blood transfusion and I was discharged home after a number of days, again to rest.

11. Within a fairly short period of time, I experienced a second fall, which resulted in a large bruise all over my face. I was taken to Barnsley General, where it was suspected that I was a victim of child abuse. I understand that my mother's midwife, who dealt with my birth was able to dispute any likelihood of abuse and so they began to look at other causes.

12. Thereafter, I was transferred to **GRO-B** where I was seen by Dr **GRO-B**

13. After having undergoing a number of tests, and within a matter of what appeared to be ten minutes, I was diagnosed with Haemophilia A at the age three years old. Apparently, the hospital was not impressed that this test had not been done before. There was no known prior haemophilia history in the family.

14. As I was only three years old at the point of my diagnosis, I naturally had little awareness let alone an idea what it was about and my parents did not fully understand what haemophilia was as a condition, or what it meant with regards to my future physical health. Over the following years, I learned what I could and couldn't do being a haemophiliac.

15. As I was experiencing frequent bleeds - around three to four times a week, I began receiving treatment for my haemophilia more or less straight away. At first, I was given cryoprecipitate, which from memory was awful. I attended **GRO-B** to receive treatment for my bleeds each time they occurred, whereby they would take big yellow drip bags and draw off this liquid into two large syringes. I would get very stressed about being administered with

cryoprecipitate, as it took a very long time to both prepare and inject. The treatment had to be administered very slowly, so that my body did not go into shock.

16. Around the same time, my mother was told that I would be in a wheelchair before I was aged twenty due to the effects of my haemophilia and the treatment I was receiving.

17. Gradually, the treatments for my haemophilia improved, and I would say that after about six months to a year from diagnosis, my treatment was switched from cryoprecipitate to Factor VIII.

18. Factor VIII treatment was a lot more convenient as it could be administered at home. My mother was taught how to inject my Factor VIII, which meant that my parents and I did not have to drive one hour to **GRO-B** to receive treatment for my bleeds. The Factor VIII also took a lot less time to administer, and instead of receiving two large syringes, I received the treatment through one smaller syringe. From the age of twelve years old, I was taught to self-administer my Factor VIII treatment.

19. I cannot state as fact whether my parents were provided with prior information or advice surrounding the potential risk of being exposed to infection as a result of receiving the blood transfusion or blood product(s) as treatment for my haemophilia. If they had, then I was not informed. As far as I am aware, the doctors believed that Factor VII was a good, beneficial and safe product.

20. However, on one occasion soon after the transition from Cryoprecipitate to Factor VII, when I was aged around three to four years old, I recall attending the **GRO-B** to receive Factor VIII treatment for a bleed, when I went into anaphylactic shock. All of a sudden, medical staff came rushing into the room and injected me with a substance - probably adrenalin but I'm unsure, to take me out of shock. We were subsequently told that the likely cause of my reaction to the treatment was that I had received a bad batch of Factor 8.

21. My Mum tells me that the doctor who administered the Factor 8 wanted to give me another shot from the same batch to check if it was that caused the problem. My Mum said absolutely "no" and Dr Lilleyman instructed them not to and to mark on my records not to give me anything from that batch again.
22. After this incident, my mother was concerned if the same thing happened when she administered treatment at home. She was just told to get me to hospital.
23. Around 1986, when I was aged around six years old, I have vivid memories of my parents and I attending [GRO-B] for a face-to-face consultation. During this consultation, my parents and I were told that there had been a bit of a blip with regards to my treatment, and that as a result, I had been diagnosed with Non-A Non-B Hepatitis.
24. In response, my mother was completely shocked and was in tears. When they came out of the room, I picked up on the traumatic reaction of my parents. Whilst I did not understand that we had just been told potentially life-changing information, I told her something along the lines of "it'll be alright mum, the doctors will fix it."
25. I believe that during my HCV diagnosis, my mother and father would have been provided with some kind of an explanation of what Non-A Non-B Hepatitis was, and what it meant with regards to the potential impact that it may have on my future physical and mental health. However, I cannot state this as fact as I was so young. I therefore, I cannot confirm whether the information would have been considered adequate enough for them to have understood and managed my infection, including the potential infection risk to others.
26. As I grew up, I formed more of an understanding of my HCV. I have since been told fairly recently that I had a very rare hepatitis genotype. The hepatologist was quite surprised and I recall that it had originated somewhere in Africa.

27. I believe that there are two potential causes of my HCV infection, both of which, are associated with my haemophilia. The first being the emergency blood transfusion I had received at Barnsley General around 1983 when I was aged three years old, as a result of blood lost due to an injury to my mouth.

28. The second potential cause of my HCV is the Cryoprecipitate and Factor VIII treatment I have received at [GRO-B] as treatment for my haemophilia, from my haemophilia diagnosis around 1983 and my HCV diagnosis in 1986.

29. I briefly recall that when I started on treatment for my haemophilia with cryoprecipitate around 1983 to 1984, this was the time in which the AIDS epidemic was surfacing. I got the impression that Doctor [GRO-B] knew that something was wrong with regards to the safety of blood treatment, but did not know what it was exactly, so he tried to keep me on cryoprecipitate as long as he could. However, at some point, probably after about 6 months, I was provided with Factor VIII. My sense was that Doctor [GRO-B]'s belief was that cryoprecipitate was safer than Factor VIII.

30. From around the age of about thirteen years old, my care was transferred from [GRO-B] to the Haemophilia Centre at the Royal Hallamshire Hospital ("Royal Hallamshire").

31. From the age of around six years old to thirty-nine years old, I attended the hospital regularly, every four to six months for a check-up where they would take blood samples for testing. This was part of the routine of having HCV.

Section 3. Other Infections.

32. Other than HCV, I do not believe that I have received any other infection as a result of receiving a blood transfusion and blood product as treatment for my haemophilia between 1983 and 1986.

33. Around the late 1990's or early 2000's, I received a letter which explained that there was a potential risk that I had received a batch of blood product which could have been infected with vCJD. I was asked whether I would like to be notified whether I had received an implicated batch, as at the time, there was no test to confirm whether I had contracted vCJD. I asked to be notified if it was thought that I may be at risk from a vCJD contaminated batch. Upon receiving this letter, I experienced a sinking feeling that this was just something to add to my other medical issues.

34. Within a matter of weeks, I was told that as far as they could be aware, I had not received an implicated batch of blood indicating that I was at risk of contracting vCJD. Whilst this news was a relief, this information was also hedged with a lot of caveats that this did not cover any future revelations.

Section 4. Consent

35. As an adult, I do not believe that I have been tested or treated without my prior consent, without my knowledge, or for the purposes of research.

36. When I received a blood transfusion at Barnsley General around 1983, this was administered in an emergency situation, and I believe that this would have been provided where it was required. I also believe that the medical profession did what was necessary in the circumstances, for the benefit of my health. In any case, I was under the age of consent, so my parents would have provided consent on my behalf. I do not know if such consent was sought in the circumstances.

37. When I was diagnosed with HCV, I do not believe that my parents were aware that I was being tested for HCV. This belief is largely due to my mother's traumatic reaction which had shown that it came as a complete surprise and out of blue i.e they were not anticipating any such news. This would indicate that they did not consent to me having undergone testing for the presence of HCV.

38. Given the period and what is now known about what was known at the time, I would not be surprised if I was also tested for HIV. However, when I was being prepared for an operation in 2012 at The Northern General Hospital, Sheffield surrounding damage caused to my ankles due to my haemophilia, I had undergone a blood test which I believe may have included HIV. I used to be asked for consent for 'blood tests' as opposed to individual specified purposes. If I had been asked, I would have provided consent for this blood test.

Section 5. Impact.

Mental/Physical Impact

39. With regards to the impact my HCV has had on my physical health, I have been very much asymptomatic. Before clearing my HCV in 2018, I had been told that the way HCV works is that it is there and it is present. It was not doing anything, but when it goes off, you do not have much longer to live. It is equivalent to a ticking time bomb in your body waiting to go off.

40. From the point of my HCV diagnosis, I have undergone numerous liver function tests ("LFT's") to monitor the condition of my liver. To date, I have not experienced an issue with my liver, but each time I attend the hospital to receive the results of my LTF, it does not stop me worrying whether this would be the time where everything will go wrong.

41. I have also undergone a number of Fibroscan's. When the results returned, I was told that I did not have scarring on my liver.

42. I believe that my HCV diagnosis has had an effect on my mental health. From the point of my HCV diagnosis and before completing my second course of treatment in 2018, I have always experienced periods of brain fog. I had a constant battle between my positive and negative mindset, though never self-destructive. On the one hand, I felt that I may not have a long time to live so I wanted to try to enjoy life. On the flip side, I had a 'what is the point' attitude,

where I questioned why I was investing time in anything or trying to be a better version of myself. I did always at least try to stay as positive as possible.

43. In addition, I experienced anxiety attacks, particularly where I am committed to a situation. These are involuntary reactions for which I cannot explain. My anxiety attacks may be from a life time of experiences where I have suppressed things and fear exposure. It is a fight between my conscious and sub-consciousness.

44. I managed my HCV diagnosis by pushing the uncertainty to the back of my mind. I used art and illustrations as a self-therapy and put everything into that.

45. Prior to having cleared my HCV in 2018, I had resisted forming a relationship due to my HCV as I did not want to put another person at risk. After I had been told my HCV was undetectable, I was able to have my first relationship at the age of thirty-nine years old.

46. As my girlfriend and I were spending a lot of time together during our relationship, I believed that it was best to inform her of my medical past. This relationship did not last much longer after I had told her about my haemophilia and HCV. I believe this information was a contributory impact on the deterioration of our relationship, alongside my lack of relationship experience. We were quite serious, it lasted eight months and we virtually lived together. I had also visited her mother with her in Australia. I did all I could to make things work.

Treatment

47. When I was in my early twenties, I was offered a course of treatment to clear my HCV at the Royal Hallamshire with Interferon. I do not recall whether this was part of a trial. They explained the side effects of the treatment, and that it could vary between person to person. This made me worried that it would have an effect on my ability to complete my degree at university. I managed to work out a period in which to get it out of the way without impinging on my studies.

48. I started on a course of treatment with Interferon for what felt like an extended period of time. I do not recall the exact length of time. Once a week, I subcutaneously injected myself in my stomach or leg.
49. I experienced side effects of my treatment with Interferon equal to severe flu-like symptoms. I felt very poorly and lousy. I was able to function with my life throughout this period, It just felt awful.
50. Throughout my first course of treatment to clear my HCV, I was regularly monitored at the Royal Hallamshire. I was told that my treatment was having a positive effect on my viral load.
51. Having completed the projected course of my treatment, I had underwent a test to determine whether I had cleared my HCV. I was told that whilst initially I was doing well, as soon as I came off the treatment, my HCV had relapsed. This left me extremely dejected and disappointed. I felt lucky that the treatment was available to me. It gave me hope and a chance initially, but this did not work out.
52. Between my first course of treatment with Interferon, and my second successful therapy in 2018, I believe that the doctors at the Royal Hallamshire wanted to wait so that treatment they could offer me was better, more advanced, and I had a better chance of success. As I was asymptomatic, they were not in a rush to treat me. They carried out regular liver tests and monitoring throughout this period. I am very fortunate that my HCV was not as bad as everyone else.
53. In 2018, when I was aged thirty-nine years old, I attended the tropical diseases department in the Royal Hallamshire, where I was told that up until that point, they were treating people with the most common hepatitis genotypes, and after this, they would refine treatment for the persons with the rarer strains. I was also told about a two-drug combination treatment of Sofosbuvir and Velpatasvir (more commonly referred to as Epclusa) which was compatible with my genotype. They had told me that they would try to obtain funding to so that I could start on a course of this treatment.

54. Within a short period of time, I was told that funding had been obtained so that I could start on my course of treatment with Epclusa. For a period of twelve-weeks, I took one tablet daily.
55. Throughout my treatment, I was monitored regularly. I was told that my treatment was having an effect on my viral load and that it was going down.
56. At the end of the twelve-week course of treatment, I was told that it had been successful, and that my HCV is now undetectable.
57. As a result of effectively clearing HCV, my life has become considerably better. It had been a rollercoaster. I have likened my HCV infection to carrying a backpack of bricks, and when I was told that my HCV was undetectable, I felt as though a weight had been lifted off my shoulders. Albeit, there was not a dramatic life change, I now have an opportunity to draw a line under it all, and do things I could not do before. For me, life did begin at forty.

Impact

58. My HCV diagnosis had quite an impact on my parents, in particular, my father who has been on anti-depressants since. A lot of bad things had happened in this period. He was made redundant from his job with the GRO-B County Council, my grandfather died, and I was diagnosed with HCV.
59. I believe that my parent's way of dealing with my HCV diagnosis was to turn to religion. When I was aged nine years old, my family became Jehovah's Witnesses. Whilst there is a paradoxical issue between the belief of Jehovah's Witnesses i.e. that it is against God's will to receive blood, and the treatment for my haemophilia, I believe that my parents always tried to do their best. This must have been quite conflicting for them as Mum had to administer Factor VIII for me when I had experienced a bleed with my haemophilia.

60. Despite growing up in this religious setting, I have always hated religion, so at the age of sixteen years old, I left the religion as a personal choice. This left me with a feeling that I did not fit into a social category of people. I had not experienced too much socialising with people outside of the fellowship. I felt very isolated which created a level of difficulty. Perhaps, this along with 'my secret' of having HCV, is why I used to experience the panic attacks when in company, particularly social situations from which I could not easily withdraw, like for instance having dinner with friends.

61. I do not believe that I have experienced the stigma attached to my HCV, as I have always kept myself to myself throughout my life. The only people who know about my HCV are my parents, my sister, my ex-girlfriend, the Skipton Fund, English Infected Blood Support Scheme ("EIBSS"), and the Infected Blood Inquiry ("IBI").

62. A large contributory factor of keeping myself private, stems down to an incident whilst I was at my first school, when a teacher told all the students about my haemophilia and that they were not to be rough with me. Of course, this had the opposite effect. Not only did it mark me out as 'special' but I became a target. I learned from experiences like this, to keep things to myself.

63. Due to my haemophilia, I had missed a lot of my early education as I so regularly had to attend the hospital for treatment.

Section 6. Treatment/Care/Support

64. I do not believe that I have faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HCV.

65. I also do not believe that my HCV diagnosis has impacted on the dental care I have received. Whilst I have seen a yellow sticker on the top of my dental records, and the dental practitioners wear gloves and PPE, I believe that these practices were necessary infection management and did not go beyond what is ordinarily employed on a day-to-day basis.

66. I have not been offered counselling or psychological support as a result of my HCV diagnosis. To be honest, I would probably have refused counselling or psychological support if it was available as I do not believe it would have been of benefit.

67. However, more recently in 2019, I had gone through a difficult period whereby I lost a friend to bowel cancer, my aunt died, and I had experienced my first break-up. When I attended a regular check-up at the Royal Hallamshire, I had come straight from a funeral in my suit. During the face-to-face consultation, I had told the doctor what had been going on in the previous months. I was told that psychological support could be made available. I did consider it but ultimately, I did not take them up on their offer.

Section 7. Financial Assistance

68. When I was in my twenties, I was told by the Haemophilia Centre at the Royal Hallamshire that the Skipton Fund were providing financial assistance for patients who had been infected with HCV as a result of receiving contaminated blood.

69. Thereafter, I made an application to the Skipton Fund, which was endorsed by the relevant medical personnel.

70. My application for financial assistance with the Skipton Fund was successful, and I received a stage one ex-gratia payment of £20,000.

71. I currently receive a monthly figure from EIBSS, which equates to a sum of around £2,400 monthly. I also receive a winter fuel allowance, however, I do not recall the exact figure.

72. Earlier this year, I received a letter out of the blue from EIBSS which stated that I was entitled to receive a further lump-sum payment of £30,000. This was in respect of the shortfall between stage one payments in England and Scotland

73. The money I have received from EIBSS has been life-changing, as it has allowed me to follow my dreams and become a freelance illustrator. Before this, I had to support myself with side jobs such as painting and decorating. The financial assistance has allowed me to evaluate what I want to do with my life, without the pressure making ends meet.

Section 8. Other Issues

74. From my own research and from documentaries that I have watched, I have seen that a lot of people have died as a result of receiving infected blood. I recall hearing that around 5,000 people have been infected with HCV and/or HIV in the United Kingdom and that 3,000 of those infected have since died. This has left me conflicted. On one hand I feel extremely fortunate that I have not lost my life or contracted HIV, but on the other hand, I feel unlucky that I contracted HCV at all.

75. I am fortunate that I live in a country that is able to provide everyone with access to medical treatment and care under the National Health Service ("NHS"). Although there have been many negative events, I believe that the intentions of the medical profession have always been good. They are good people who are trying their best. But for the treatment I have been provided with, I would probably not be here today. I am very grateful.

76. However, from what I understand, I do believe that there is a level of culpability at a government level with regards to the contaminated blood scandal. Both England and Scotland had a decision to make surrounding the importation of blood, and it appears that Scotland were able to react quicker than England. This resulted in more people being infected in England.

77. In day-to-day life, people are consistently defined. For example, they are defined by their profession; plumbers, doctors, and electricians. Overall, although technically I am a victim of the being given infected blood but I do not want to be defined as a 'victim'. I have never wanted to be judged, looked at,

or for people to make allowances. I want to be an equal. I do not want to be looked upon as a 'victim'.

78. From a very young age, my experiences have taught me that life is fragile, and that there is always someone who is a lot worse off. This is how I rationalise what has happened. Life is cruel at times but it is also wonderful. At first, I thought why did this happen me? But then once I knew more about it, I thought why not me? It has to happen to someone. I have had a life experience that is significantly different, compared to the majority of my peers, and this forms part of who I am. It is my history and it has taught me to appreciate what I have got. There are a lot of people who would love to be happy and healthy. After all, what doesn't kill you makes you stronger. You try to turn the bad things into good. You cannot control everything, but what you can do is transform the bad into something better.

79. Even if providing my witness statement is just a small part of the overall Inquiry, I have done so as I want to honour all those people who have been infected, affected by a loved one's infection or who have lost their lives to the contaminated blood scandal.

80. This process has been cathartic for me and helps me in trying to draw a line under my personal HCV story.

Statement of Truth

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

Signed

GRO-B

Dated

16/12/2021