

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0383001

Exhibits: None

Dated: September 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows: -

Section 1: Introduction

1. My name is GRO-B and my date of birth is GRO-B 1984. I reside at GRO-B. I have severe Haemophilia B and I am making this statement to discuss the impact of contracting Hepatitis C from contaminated blood products provided to me by the NHS. My brother also has Haemophilia B.
2. I live at home with my wife, GRO-B who I met at GRO-B University in 2003. We got married on GRO-B. We have a daughter called GRO-B. GRO-B is only seven years old, but understands and knows everything about my Haemophilia. She will even sit and watch me administering my factor 9 treatment and often help to mix my products.
3. I work four nights a week at GRO-B and look after GRO-B during the day. I grew up in GRO-B, Lincolnshire and I have been an avid fan of Leicester City Football Club since I was a child. I also like to play golf when I am able to.
4. GRO-B and my mother GRO-B have also provided statements to the Inquiry to discuss the impact that my infection with Hepatitis C through contaminated

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blood products has had on them (WITN3196001 and WITN1050001 respectively).

5. My mother's statement provides more information about my treatment and care when I was child. I am aware, however, that I was diagnosed with severe Haemophilia B when I was around six months old and diagnosed with Hepatitis C when I was nine years old.

Section 2: How Infected

6. I am aware that I suffered frequent bleeds as a child and that I was treated at Lincoln County Hospital ("Lincoln") for those bleeds with factor 9 products under the care of Dr Pragnall and Dr Adelman. I understand that I received seven treatments of Factor IX in 1985. When I was nine months old, Dr Pragnall told my mother that I was possibly showing signs of "non-A \ non-B Hepatitis", as Hepatitis C was previously known, but that "alternatively it could just be lethargy".
7. I understand that Lincoln Hospital endeavoured to give their patients British blood products, but this was not always possible, particularly for patients like me that were being treated with factor on demand. My parents, and parents of children like me, therefore had no choice but to accept whatever blood products were available on the NHS at the time treatment was needed.
8. I was not officially diagnosed with Hepatitis C until May 1993, when I was around nine years old. I am aware that I was diagnosed with the genotype 1 strain of Hepatitis C. I cannot remember being told about contracting the virus at the time because I was still a young child. I imagine that I just did everything my parents asked me to do, in relation to living with the virus and taking any necessary precautions regarding transmission.

Section 3: Other Infections

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9. I am aware that when I was nine years old in May 1993 it was confirmed at my 6 monthly standard review appointments at Lincoln County Hospital with my Mum who was present, it was not an appointment to tell me just a routine appointment. My parents were not asked about taking the test 2 years prior in 1991 as we were only told of my infection state in 1993. We were told that it was a mild infection and should not be any concern. Verbally being told that I had contracted Hepatitis C, but that I had not contracted HIV.
10. When I was in The Sheffield Hallamshire Hospital, I contracted MRSA and Clostridium difficile (C. diff), both of which are bacterial infections. I had to have three clear tests of stool samples before it could be confirmed that I had cleared these viruses and this still follows me around as if I have any further treatments or procedures, I have to follow a cleaning regime with specialist medicated wash and nasal cream prior to a hospital visit and carry out a test before to ensure I am clear from MRSA.
11. In April 2000 I received a call from Dr Adelman at Lincoln Hospital regarding potential exposure to Variant Creutzfeldt-Jakob disease ("vCJD"). He did not give me much information, other than to inform me that I might have been exposed to vCJD through some of the Factor IX I had received and that he had a further nine families to tell due to boys living in Lincoln under the centre's care having recent diagnosis. This was a stressful and worrying time for me. I was given the batch numbers over the phone of potentially infected blood products that I had been given. I had to check all the bottles of Factor IX I had been given and send any that might be infected back to Lincoln Hospital for testing.

Section 4: Consent

12. As I was diagnosed with Hepatitis C as a child, I do not recall being tested for Hepatitis C, or any other virus. I am aware, however, that I was tested in around 1993. I believe my mother was aware of exactly when and where I was tested for both Hepatitis and HIV and she discusses this in her statement to the Inquiry.

Section 5: Impact

Impact of being infected with Hepatitis C on me and my family

13. I believe that my mother and father felt like it was their fault that I contracted Hepatitis C and blamed themselves, despite there being no choice but to accept whatever blood products were available at Lincoln Hospital at the time I needed treatment as it was a life-or-death decision for them to make with the severity of bleeding I was suffering.
14. It is quite difficult to recall my early childhood, but I remember some children saw me as different to them and treated me like I was diseased. It was a struggle to make friends as I felt I would need to be honest with them even in a close-knit friendship group about my condition. This made me feel secluded at times, particularly in high school where I had a lot of absences through illness. However, some children were more sympathetic towards me given my condition. These experiences were due to me having Hepatitis C and Haemophilia B. I am also aware that my mother encountered difficulties with finding a childminder to care for me whilst I was a child, as a result of my Hepatitis C infection. One childminder even said something along the lines of *"you cannot bring him here because he might infect other children"*. These experiences were due to me having Hepatitis C and Haemophilia B and the lack of knowledge that people had at the time.
15. I think my mother and father protected me a lot when I was child, so I did not feel as much of an impact of living with Hepatitis C as others may have experienced. I was still able to take part in activities like cubs and scouts and I was only really restricted from things like contact sports. I am not sure if this was because of a fear that I might suffer a bleed because of my Haemophilia B, or because of the fear of Hepatitis C and the risk of transmitting the virus to another care giver.
16. I am very comfortable with talking and discussing my Haemophilia B with others, but have always been reluctant to administer any treatment in front of other people due to judgement or questioning of why. I have found it more difficult to talk openly about having Hepatitis C, mainly because I do not know how people

will react. I think it has had a huge impact on my confidence, particularly when dating, because I feared being rejected just for having the virus. People did not know a lot about Hepatitis C. I did not tell GRO-B about my Hepatitis C diagnosis until we had been friends for around six months.

Treatment for Hepatitis C and its impact

17. Following my diagnosis in May 1993, I had to undergo three separate treatment courses in order to clear the Hepatitis C virus.
18. I recall that I was first given Interferon to treat the Hepatitis C virus in 1995, when I was around 11 years old. I had to take the medication at 12:30pm on Mondays, Wednesdays and Fridays. I was initially given a dose of three million units, but this dosage made me sick and gave me headaches. As such, the dose was reduced to one million units for a period of time before being increased to two million units. My Doctor, Dr Lawrenson said he would support me if I wanted to stop the medication, due to the sickness and headaches, but he explained it might just be the side effects of the treatment. I also developed rashes on my body during this treatment. It became increasingly hard to continue to medication offered so did not complete the course of treatment.
19. I believe that this treatment impacted on my education at the time because I was feeling lethargic a lot of the time and lacked motivation. I was reluctant to do basic things like get up and get dressed in the mornings. It is strange to think back to this time because I am unable to say if this was normal for any 11-year-old, or if it was because of the Hepatitis C treatment upon my body.
20. I cannot remember if I was tested for Hepatitis C again after I had finished this first treatment course in 1995. I assume I must have been tested and the results confirmed that I had not cleared the virus, because I had to have further treatment.

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21. In 2002 I was given a second treatment course consisting of Interferon and Ribavirin to try to clear my Hepatitis C. I recall that I had similar side effects to those I experienced when I was given the first treatment course with just Interferon, as mentioned above. I was constantly feeling tired. I was also reluctant to take this treatment because it required me to inject myself into my right side of my stomach and this sometimes made me vomit. It was very uncomfortable on occasions.
22. I had just started studying at GRO-B University by the time I underwent the second treatment course. I was originally studying for a degree in aerospace, but I was unable to complete this course and changed my degree course to sport development. The aerospace course was just not the right course for me which is why I changed my course however; I believe that the treatment for the Hepatitis C had an impact on my studies because it affected my concentration levels. I really struggled to self-motivate and go to the library to study for longer periods of time. I was unable to socialise as others were doing and attend all of my lectures. The aerospace course might not have been the right course, but I still think the treatment for Hepatitis C adversely affected my studies whilst at university and was a factor in my decision to change my degree course.
23. During the second treatment course, I also developed glandular fever and laryngitis. This meant I lost around three stone in weight very quickly. Around this time, I transferred my treatment from Lincoln Hospital to Sheffield Teaching Hospital ("Sheffield") to be under the care of Dr Mike Makris.
24. Following the second treatment course, it was confirmed to me that I still had not cleared the Hepatitis C virus. I was hugely disappointed and frustrated. In 2006 I recall being really close to the edge and I was not myself. My personality was changing whilst I was ongoing the next treatments. I was feeling suicidal on occasions and was having thoughts of (jumping off the bridge over the M61.) In hindsight I can see that I was really depressed and on one occasion, I even attempted to hurt GRO-B. I remember pinning GRO-B up against the wall in our house and yelling at her, which is completely out of character for me. I believe this was

due to the lasting side-effects of the second treatment course that I underwent to clear the Hepatitis C virus. As a result of these side effects, I went to my GP in Bolton as I wanted an explanation for this behaviour. Unfortunately, I was not given any more information or offered any therapy at that time.

25. On 2nd November 2016 I underwent my third treatment course to clear my Hepatitis C with the support of GRO-B. This was a combination of Viekirax and Exviera, which had to be taken in a tablet form. During this treatment, I was under the care to Dr Makris in Sheffield and he really has been amazing. I have him on speed-dial on my telephone. He has always been really supportive and given me lots of information about new treatment's, therapies exactly when needed. I remember him calling me to discuss the various treatment options available to me and sharing the information with me prior so I felt like I had ownership of my treatment choices before I started this third treatment. This was completely different to my experience at Lincoln, Hospital where I believe they just give you the cheapest available treatment to their patients.
26. As part of this third treatment course, I was also provided with a diary to track my moods. It makes me angry to think back to the first two treatments and what I had to go through, given that the third treatment was easy by comparison, particularly given this treatment was taken as a tablet, rather than injection. It was a 12-week course and I had to have regular blood tests and liver function tests to monitor the progress of the treatment. I kept a record of my viral load in the diary given to me at the start of the treatment course, which records the viral loads as follows:
- a. 01 November 2016 – 28,882,410
 - b. 23 December 2016 – 11,800,010
 - c. 26 January 2017 – 108
 - d. 28 February 2017 – no trace
27. I think the diary really helped, because I was able to tick off the number of tablets, I had left each day and I was able to see the progress with my decreasing viral load. It kept me motivated to carry on. I was given regular phone calls to check

in and was always seen by the same nurse at clinic. I felt like a human being and not just another patient.

28. Whilst my tests were showing no trace of the Hepatitis C virus from 28 February 2017, I was told that the virus could still recur within the next three months, so I required further tests. Thankfully the Hepatitis C did not reoccur. I told my mother that I had cleared my Hepatitis C virus on her birthday. I remember her crying when I told her the news. I also remember one of the nurses at the Sheffield Haemophilia Centre also became really emotional when I told her which was lovely as we had all had the experiences together. They were my support network.
29. The feeling of relief that the treatment had worked and realisation that I had cleared the Hepatitis C virus did not hit me straight away, because I had lived with it for so long. It still feels weird today thinking I am now clear of the virus. It is the mundane things, like filling out insurance forms and not having to declare that I have Hepatitis C, which feels strange.
30. Whilst I have cleared the virus, I still have a low immune system and I frequently have a cold. It also takes me a lot longer to recover from illnesses like colds. I also suffer from memory loss and constantly have to be prompted to do things so I still need some support.

Impact on my marriage

31. In 2010 [GRO-B] and I were planning to start a family. [GRO-B] and I were advised by Dr Makris and the nursing team at Sheffield that Hepatitis C could be sexually transmitted and this initially delayed our plans for starting a family as we wanted to know more and be as safe as possible. [GRO-B] and I were aware prior to this that Hepatitis C could be sexually transmitted as my mother had told us. We both wanted to start a family together but we also wanted to be careful not to rush because of treatments available and neither of us wanted to live with the fact that we may pass on hepatitis to our baby. I was very scared and frustrated

as I did not want to give it to GRO-B or a potential baby. I felt like it was my fault as I was the one suffering with this diagnosis.

32. Living with Hepatitis C also impacted holidays for GRO-B and I. We both enjoy travelling. In 2005 GRO-B and I were on holiday in Prague and I was undergoing treatment for Hepatitis C at the time. The treatment involved an injection into my stomach. One day, a lot of puss started discharging from my injection site. It looked like spaghetti. We were concerned by this and so we had to cut our holiday short and return home so I could attend The Sheffield Hallamshire Hospital to be checked out and treated. When we returned home, the doctors confirmed I had contracted an infection in the injection site. I had to stay in hospital for treatment. This would not of have happened had it not been for the treatment for Hepatitis C.

Impact on social life and stigma

33. Being infected with Hepatitis C also impacted my social experience at university. I did not drink a lot of alcohol during my time at university because I was advised not to drink it by my parents as they had tried to research as much as possible to naturally help me to maintain a good liver. I would not be where I am today if it were not for my parents' guidance. I am aware of someone also infected with Hepatitis C that drank large amounts of alcohol and sadly he has since passed away. If I did not have Hepatitis C my experience at university would probably have been very different. I sometimes think of the opportunities I could have had, if I had not contracted Hepatitis C.
34. Whilst at university I did not really tell people about my diagnosis with Hepatitis C. I suppose it was the stigma and the questions that stopped me from being more open. I did not want people to ask "how did you get it" or believing I used a dirty needle. I also believed that people would link Hepatitis C with HIV and because it was very negative press which followed the diagnosis of Hepatitis C and HIV I was very cautious.

35. Thankfully the Inquiry is helping to address the stigma around Hepatitis C and HIV by raising more awareness. I did not realise how big the scandal was until the Inquiry started. I have always thought of having Hepatitis C as a sort of silent disease that I have had for as long as I can remember.

Impact on work

36. Prior to commencing my job at [GRO-B] in 2015, I worked at [GRO-B]. At [GRO-B], I remember one manager being quite rude about my need to have a separate first aid box because of the risk of transmitting Hepatitis C and if any treatment were needed to double glove etc. He did not understand. The Trade Union had to get involved in order for me to be given special allowances, including a separate first aid box. This led to me being talked about at work by other colleagues which in turn made me feel very isolated.
37. [GRO-B] gave me a 25-day allowance for taking time off work related to the treatment of my Haemophilia and Hepatitis C, but this was quickly used up whenever I had an extended stay in hospital. On one occasion I confronted one of my managers because he asked me to specify what condition (Hepatitis C, depression or Haemophilia treatment) that required me to have additional time off work on a specific occasion. This manager even visited me at my house in order to assess my health.
38. As mentioned above, I now work at [GRO-B] and they have been really good compared to my experience at [GRO-B] as an employee.
39. In 2015 I had an accident at work when I was hit on the head by a barrier. This accident resulted in me having to go to Manchester Haemophilia Hospital ("Manchester"). I did not routinely receive treatment at Manchester, but it was the nearest hospital following the accident. Whilst at Manchester, I was segregated from other patients because of a risk of transmitting Hepatitis C. All my visitors, including my family, also had to wear protective clothing when they came to visit.

This again led me to feel isolated and looked upon and judged. It was not something I had done to myself and in turn I was not to blame for having hepatitis C.

Impact on finances

40. The main financial impact of having contracted Hepatitis C is the extra trips needed to go to hospital. The costs quickly escalate with the additional petrol, parking tickets and time taken off from work. If you need an extended period of unpaid time off work, it does not help. [GRO-B] are more flexible with this but I encountered some difficulties when I worked at [GRO-B]
41. I have only ever been able to work part-time and [GRO-B] is the main earner in our family. When I was undergoing treatment for Hepatitis C, I was so tired all the time. If I work long hours, I become ill really easily. I also had a period of sick leave in 2006 due to depression as a result of the additional stress of trying to provide for my family and worrying about paying our rent and the bills.
42. Having Hepatitis C also impacted on other things like the costs of travel insurance and it became a barrier to getting life insurance. Thankfully The Haemophilia Society assisted with obtaining cheaper holiday insurance whilst I still had Hepatitis C., I still cannot get life insurance today, which has prevented me from being able to get a mortgage [GRO-B] and I had to rent for 13 years before [GRO-B] took out a mortgage for home security in her name only.

Section 6: Treatment/Care/Support

Treatment and counselling

43. I do not recall being offered any counselling or other support as a result of contracting Hepatitis C during my first two treatment courses to clear the virus. When I started the third treatment course in 2014, I was offered a counsellor who was available on the telephone to provide support and advice when needed. I

thought this was very helpful. Given my positive experience of counselling, I believe it would have been useful if counselling and support was offered during the first two treatment courses. There was a complete lack of support during those first two treatment courses, in comparison to my recent treatments.

44. Given my experience of living with the virus and treatment of the same, I think that all hospitals and the care received under them should be like that in Sheffield. Everyone within the Haemophilia Centre in Sheffield is like a family to me. Dr Makris and Sister Harrison are superb and very professional/ They are all well read and offer a helpful ear about all sorts of things. They support the whole family and the whole patient from social workers, physio and specialised nurses. There was no separate care facility at Lincoln Hospital like there is in Sheffield. Sister Brown at Lincoln Hospital was the only support network I had and she was always honest.

Obstacles to treatment

45. Whilst I live in GRO-B I have remained under the care of Dr Makris at Sheffield. I did not have a good experience at the Manchester Royal Infirmary (the "MRI"). I was admitted to the MRI in 2011 with an ear bleed and I found Dr Charles Hay in the Haemophilia Centre to be very rude. He spoke to me like I did not know anything about Haemophilia B. He also wrote to Sheffield 'behind my back' to try and poach me as a patient, which I thought was very strange, and that was all he seemed to be interested in. In my opinion it was because I was so eager to try new treatments and therapies to help both my Haemophilia B and my Hepatitis C and he wanted a new study. There were also issues with him being late for appointments and he spoke to me about my brother's haemophilia treatment despite the fact this was a breach of patient confidentiality.
46. My issues with the treatment at the MRI mainly refer to the Haemophilia Centre, rather than other departments of the hospital. When GRO-B was pregnant with GRO-B we had to attend St Mary's for a scan and conversation about our delivery. Dr Hay on this same occasion only seemed interested in me becoming

a patient at their hospital. However, the maternity ward at St Mary's hospital, which is part of the same NHS Trust at the MRI, were fantastic. They treated us like normal people and respected us. They fully supported [GRO-B] and I and bought little [GRO-B] into the world safely. I consider Dr Hay in the Haemophilia Centre lacks basic people skills and does not see the patient as a human being. He in my opinion does not see the whole family picture or gives people/the patients their own right to choose for themselves and I therefore choose to drive to Sheffield Comprehensive Care centre for my Comprehensive Haemophilia care as they are superb and I only wish everyone's experiences of their comprehensive care centre were as good as what I have now at Sheffield Hallamshire Hospital.

47. I have also experienced some difficulties as a result of both my Haemophilia B and Hepatitis C whenever I had to visit the GP or dentist. When attending appointments at my regular dentist in [GRO-B], I have always found that he has been dubious to touch me, clean my teeth thoroughly, but this might just be because he is worried, I might suffer from a bleed after treatment, and does not really understand Haemophilia, rather than him being worried about my Hepatitis C. My GP in turn is often very reluctant with some treatments or looking at injuries I may have due to the lack of knowledge about my condition.

Section 7: Financial Assistance

48. I received £20,000 from the Skipton Fund in 2002 as a one-off payment. Separately I also received a larger fridge to store my Factor IX concentrate in. I felt like the Skipton Fund made me jump through a lot of hoops, particularly for the fridge, and there were lots of forms to complete prior to a decision.
49. I now receive regular payments from the England Infected Blood Support Scheme ("EIBSS") which started in October 2017. The Haemophilia Society helped me to complete the forms and apply for it. I recall it also had to be signed off by a doctor to confirm what stage of Hepatitis I had, but I encountered no difficulties with this. It was much easier than the Skipton Fund.

50. Last year I completed the Personal Independence Payment ("PIP") forms as this changed from DLA which I was entitled to 'indefinitely'. I had to change and apply to PIP to help with the extra costs of living with severe Haemophilia B. The form was a nightmare to complete and I had a huge amount of support from the social worker at Sheffield Hospital. I also had to undertake a medical assessment; I was told I was 'ineligible'. The medical assessment in my opinion was too rigid and points were scored based on how you were on the day, rather than looking at the illness as a whole. I felt like the assessors were not properly looking at me when carrying out the assessment, or that they were sufficiently trained to properly understand what it is like living with Severe Haemophilia B. It was a very stressful process which I also appealed with the support of the team at Sheffield Hospital.
51. I appealed the decision with the help of The Haemophilia Social Worker at Sheffield Hallamshire and I now receive PIP allowance to help with the additional costs of living with Severe Haemophilia B.

Section 8: Additional information and conclusion

The Haemophilia Society

52. As a child I used to go to all of the summer camps with The Haemophilia Society and even went to places like Vancouver in Canada as a youth delegate for the UK. There have always been organised events to attend, like weeks away at places like PGL and Barretstown for members to enjoy.
53. I have always been involved with The Haemophilia Society and I was the treasurer for the local Haemophilia group in the [GRO-B] from 2015 to 2016, before it ceased to support the local area [GRO-B] and I attend all of the Annual General Meetings of The Haemophilia Society, and regularly volunteer for day events.
54. I have always been part of the [GRO-B] Haemophilia group and my mother was involved when it was first established. [GRO-B] and I volunteer with the

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GRO-B group to help raise awareness of Haemophilia and Von Willebrand's, and we take part in fundraising events. I have been **GRO-B** of the **GRO-B** group for around 8 to 10 years, but I feel like now is the time for the younger members to take on this role and help drive the group forward so I now have decided to step down from this role.

Conclusion

55. I feel angry about the contaminated blood scandal and the products not being heat treated properly. I am hugely frustrated with the impact and missed opportunities I feel I have not had due to contracting Hepatitis C. I contracted Hepatitis C at such a young age, therefore I seemed to just managed it, but the lasting impact it has had emotionally and physically on me and my close family especially my parents can never be eradicated.
56. I did not know anything different until recently when I cleared the virus and whilst I do not blame individual doctors for treating me with contaminated blood products, I believe the NHS and/or the government knew that the blood products being used to treat conditions such as Haemophilia were not safe or at their safest and were still allowing them to treat individuals. Therefore, I would like an apology which we have never had from anyone of any power or position. I would hope the Inquiry can provide answers regarding why people were treated with contaminated blood products in the first place and offer further guidance to ensure that this never happens again.

Statement of Truth

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

Signed

GRO-B

Dated

17.09.21