

Witness Name: GRO-B

Statement No.: WITN4299001

Exhibits:

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 31 July 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1984 and my address is known to the Inquiry. I am married with no children and I live in my own home.
2. I am a healthcare professional and I work as a Prosthetist, i.e. concerned with artificial limbs. I have 3 siblings but I am the only one that suffers from Beta Thalassemia Major, a condition that I will go on to explain and it is entirely relevant to the purpose of this statement.
3. I intend to speak about my Thalassemia and subsequent infection with Hepatitis C. In particular, how the illness affected me, the treatment I received and the impact it had on me and my family's lives.

Section 2. How Infected

4. I was born in Algeria and was diagnosed with Beta Thalassaemia Major when I was about a year or 18 months old. My condition means that I can't produce enough of my own healthy red blood cells, and as an adult, I have to receive blood transfusions every three weeks.
5. My mother and father are Iraqi. They fled Iraq during the Iran/Iraq war of the 1980s and settled in Algeria where I was born in 1984. Dad was a civil engineer, working in various countries in the Middle East. We subsequently travelled to Switzerland and according to my parents, I was transfused with 2 units of blood due to my condition. I may have had 1 blood transfusion in Libya. Due to the international situation in the Middle East, we had to leave. With the help of the Red Cross, my family moved to Hungary, where we stayed for about 2 years. During this time, I received a transfusion of one or two units of blood. I was far too young to recall any of this but my mother has a good memory and I referred to her for this information.
6. We moved to the UK in July 1987, when I was about 3 years old. My first blood transfusion in the UK was at Queen Mary's Hospital in Paddington.
7. Shortly after, we moved to GRO-B and I continued to receive blood transfusions at West Middlesex Hospital, Isleworth. Between 1987 and 1988, I was transferred to see Professor Hoffbrand, a Haematologist, at the Royal Free Hospital. The main doctor responsible for my care was Dr GRO-D. According to my mum, in 1988, I was transferred from the Royal Free hospital to Whittington Hospital, in North London.
8. During this period, I was receiving two to three units of blood, transfused every three to four weeks. I have asked my mother if she was ever told of any risks associated with blood transfusions. She was not. However,

I accept that any risks would have had to have been balanced against the risks of not being transfused.

9. According to the medical textbooks, I would have died by the age of 21 or 22 if I had not received any blood transfusions. It would have been a slow and painful death. Without the blood transfusions, I would also have been weaker, and my puberty would have been affected.
10. At the age of 8, I went into the Royal Free hospital for a splenectomy. After carrying out some tests for the surgery, I was diagnosed with Hepatitis C. I was informed that the liver function tests showed damage to my liver.
11. My diagnosis came as a complete shock to my family because I had shown no symptoms. As I stated earlier, I have no direct memory of this part of my childhood and the information I am providing about my diagnosis is what my mother has told me. She told me that Dr. GRO-D delivered the news of my HCV+ status, in person, at a regular visit.
12. My mother recalls vividly that Dr. GRO-D was cold and dismissive when she was informed of my diagnosis. There was no explanation at that time that it was known that there were contaminated blood supplies in the UK. My mother is still upset today about this and the manner in which she was informed.
13. I had to see a doctor regularly for my Thalassemia, but the Hepatitis C diagnosis meant that I had to see another specialist. It meant that I had to spend a lot of time outside of school and explaining to my teachers and friends about being out of school. It affected me a lot, being away from school and being 'different'. I remember crying a lot as a child. I looked visibly jaundiced which also affected me psychologically. It made me self-conscious about how I looked. I was also very worried about liver cirrhosis.

14. The biggest problem that restricted me the most in my life was not my Thalassemia but Hepatitis C. I was told that I had to be careful not to infect my family members, which affected me a lot in terms of the responsibility and the risk.
15. I had to keep my toothbrushes separate, if I had a cut there would be a big activity around the house. It affected me psychologically and I was very conscious when playing physically with my younger brothers. When I started shaving, we had to hide my razors away from my younger brothers in case they tried to mimic me and 'shave' using my razors. This made me feel dirty and put a heavy burden on me to be vigilant and not infect my family members.
16. I have never been an intravenous drug user and I have no tattoos.

Section 3. Other Infections

17. I do not believe that I have received any other infection other than Hepatitis C as a result of being given infected blood or blood products.

Section 4. Consent

18. As far as I am aware, no treatment or tests have been conducted on me without the knowledge of either my parents, when I was a child, or myself as an adult.

Section 5. Impact

19. Being diagnosed with Hepatitis C has had a major impact on my life. It has had an impact on my previous relationships and my current relationship with my wife. A number of my relationships broke down because of my Hepatitis C.

20. From 2003, when I was around 19 or 20 and at University, I decided that I would like to get married because a lot of my friends had started talking about marriage. I consider myself a very religious person and culturally boyfriend-girlfriend relationships were unheard of, so the only route to finding a companion was the traditional route, by family arrangement.
21. It was important to me, to be honest in my relationships. Because of the information I had received from the doctors, I was concerned about transferring Hepatitis C through sexual intercourse and this prevented me from having sexual relationships.
22. Between the ages of 22 and 29, I could not get married because my Hepatitis C diagnosis was a 'deal breaker'. I later found out that the risk of transfer was very minimal which made me hopeful. However, because about 90% of my relationships were within the traditional arranged marriage context, the families would not allow the relationships to move forward.
23. After over 25 failed attempts, I had given up and planned to remain alone. I did however meet my wife when I was 29. My wife conducted her own research and spoke with a specialist independently. She had to convince her family that the risk of transferring Hepatitis C was minimal. Her father had said to her, "this is like suicide". This caused me much anguish and hurt because I dearly loved my now wife because of her understanding and belief in what I had explained to her. Until this day this has severely affected my relationship with my Father in law and I feel he is disappointed in her selection. This has caused untold problems between us and has made me feel less worthy as a husband and a son in law.
24. My Hepatitis C diagnosis has also affected my marriage. It plays on my mind. Particularly, the stigma from the community. My wife has never

been tested for Hepatitis C but there is a chance she could have contracted it before I had the treatment. I haven't investigated it and I don't want to. My fear is that I will lose her if she has contracted the virus. I live in hope and pray that she has not been infected. However, I now believe it is the right thing to do, and will organise for her to be tested.

25. My relationship with my wife is a healthy one. However, I always feel guilty after sexual intercourse as I always feared I would be putting her at risk. This has immensely affected my sexual relationship with her and has had a negative impact psychologically in a sexual way to this day despite being cured of Hepatitis C.
26. Because of my Thalassaemia, I have an iron overload in my heart and my liver. Iron collection in some part of the body is a common side effect of Thalassaemia. However, the iron overload in my liver was caused by Hepatitis C, because my liver function was already compromised because of the Hepatitis C. This leads to further iron overload in the liver as the liver is unable to shed the excessive iron it stores. As soon as my Hepatitis C was treated the iron collected in my liver cleared off quickly afterwards.
27. However, clearing iron in the heart takes a lot longer. The Hepatitis C infection exacerbated the iron overload in my heart due to the years of harbouring the virus in my liver. When I was in college about 16 years old, the iron levels in my heart got so high that the doctors had to install a portacath to flush it out which worked for about 2 months until it got infected. I had to be rushed into A&E because this was life threatening. I could not breath without a severe stabbing pain in my chest. This was the first time I felt that I was going to die and has always haunted me until this day. This severely affected my exams as it was the last year of college and had a detrimental effect on my university application.
28. I was due to start a degree in Medical engineering with a connection to a secure engineering job after completion. However, due to the infected

portacath emergency I was unable to gain the exam results required for engineering. I was forced to find alternative careers that were not as secure and lucrative. I was forced to use the clearing process in a course that I didn't even desire. My heart was set on engineering.

29. At university after my second semester I was wrongly informed by my university health nurse that I was vulnerable and could not continue the course I was on as it was a course that involved dealing with vulnerable patients. I was apparently a risk to my future patients due to my Hepatitis. This severely affected my motivation and my attitude to my degree. It made me depressed as I had started to enjoy the course. This wrong information from the health nurse affected my grades and caused me to graduate with a lower than expected grade. This had also affected many job applications and I had a delayed start to my career.
30. My heart function remains compromised until today. Doctors have said it can take 5 - 6 years to clear the iron overload. Since Hepatitis C was treated there have been signs of progress but if it hasn't cleared in the time expected it is a cause for concern by my heart specialist. He explained to me recently that I may have to start taking heart medication in order to prevent potential heart failure. I am currently undergoing iron collation therapy and I have a 24-hour slow release injection pump installed permanently in my arm. This is the only method available to me in order to improve my heart health. This is a very impractical and painful treatment as I have to inject myself every day and leave the injections (Thalaset) in my arm whilst I carry the pump in my pocket. The pump has been noticed by a number of my colleagues and patients and has led to some very embarrassing conversations.
31. My Hepatitis C diagnosis also impacted my education. My spelling, numeracy and the ability to read have been affected. I believe that this is because of the gaps in my education, due to all the time I spent away from school for the hepatitis treatment. At college, I had to be tested for dyslexia but I found out that I wasn't dyslexic.

32. My current job involves writing legal documents for clients who have suffered a road traffic accident. This has led to being corrected and told of my grammar and spelling mistakes multiple times by associates, clients, and colleagues. It has always been a limiting factor in my career progression and I find this very embarrassing.
33. Spending time away from school also had a knock-on effect on self perception among my peer group. In terms of my education, I would say hepatitis was responsible for about 60% of the disruption with 40% due to my thalassemia.
34. However, after complications from my Hepatitis C led to more hospital visits, the proportion shifted to 60% of the disruption being because of Hepatitis C and 40% due to the iron overload on my heart.
35. I was conscious every time someone put a needle in me because of my Hepatitis C status. I noticed that people took more precautions around me but I wanted them to be conscious of that because I did not want the responsibility of infecting someone.
36. In Manchester, one of the nurses accidentally pricked herself after a failed blood test and I could see her face drop when I informed her that I had Hepatitis C. This is indicative of living with HCV and the risks associated. I believe the nurse later cried and had to be consoled by her colleagues. This made me feel immensely guilty despite it not being my fault.
37. I confided in only my closest friends about my Hepatitis C because I was ashamed of having it. I didn't tell other friends because I did not want them to be concerned about the chances of contracting it from me. I also did not want the stigma of people wondering how I contracted it or assuming I had a dirty lifestyle. My relationships with friends who I shared this information with seemed to gradually become more distant.

I believe this is a result of them fearing they would be infected from handshakes and close contact.

Section 6. Treatment/Care/Support

38. Following my diagnosis with Hepatitis C at 8, I was given a short course of interferon, for a period of 2 - 3 months. We were told that the side effects meant I would need more blood. I had to go to the hospital every week for a transfusion instead of every 3 weeks
39. They also said that I could become depressed as a side effect of the drug. My mom says I cried a lot and was fatigued. Luckily, I don't remember all of it as a child, although I do remember the crying and asking why am I inflicted with this virus.
40. My mom says it was very traumatic for her, my dad and my older sister. I can't remember how I received the Interferon. It was a tough treatment but it was unsuccessful.
41. Before I went to university, around age 17 or 18, I was offered a second treatment which would be a combination therapy of Interferon and Ribavirin. However, I was told that this treatment would require me having more regular blood transfusions related to my Thalassemia and could also bring on depression, so I put off receiving this treatment for a few years.
42. In between my first treatment and the second treatment, I had to have three very painful liver biopsies. These are the most painful medical procedures I have had to endure. I always feared this procedure, causing me much stress and anxiety.
43. By 2008, after I had graduated from university, the doctors understood hepatitis a lot more and I was told that my genotype was a lot harder to treat and the treatment success rate for my particular genotype was only

10% or less. If I had received this treatment at 17 or 18, it was likely that it would not have worked, and it would have been a painful and traumatic experience for me.

44. I finally had my second treatment at age 31. It involved taking 1 tablet a day for six months and did not involve any injections. I received this as a participant in the MERCK clinical trial. This treatment was known to be effective with my particular genotype. My wife accompanied me for my hospital visits during this clinical trial as she was very concerned it would not work and wanted to learn and implement everything needed to ensure I had the best chance of being cured.

45. I did not suffer from any side effects. However, I have permanent scarring on my liver due to having hepatitis C for 22 - 23 years. I have to see a liver specialist every year because of the scarring. I have also had a few cancer scares because of the way the scarring sometimes appeared on scans. This had led to many worrying and depressing conversations with close friends and family members.

46. I have never been offered counselling or psychological support and I do wish I had been offered such support. The psychological effects of having Hepatitis C remain today, in how I see and present myself.

Section 7. Financial Assistance

47. As a result of having thalassemia, I have four friends, who are thalassaemic who also have or have had hepatitis C, and they informed me about the Skipton Fund. My doctor also confirmed this information.

48. In 2006, at the age of 22, I made an application for financial support to the Skipton Fund. However, my application did not progress because apparently, the doctor had not completed the form confirming that they had viewed my records regarding blood transfusions that I had received.

49. I do not know why I did not follow this up, but it may have been because I was at university in Manchester and the letter was addressed to my home address in Middlesex. I fully intend to follow this up and I am in the process of applying to the English Infected Blood Support Scheme as I believe that it is most likely that I received Hepatitis C through one of the numerous blood transfusions I received in England during a period when it is now well known that there was a lot of contaminated blood within the UK blood supplies, rather than the three or four blood transfusion that I had received as little more than an infant prior to coming to the UK.

Section 8. Other Issues

50. I currently have blood transfusions for my Thalassemia every 3 weeks at the Whittington Hospital in Archway. I have to have three units of blood and each unit takes about 2 hours. Assuming there are no complications I could be in the hospital for 6-8 hours. I also have to go in a few days before the transfusions to do a cross match with my blood and the blood I will receive.

51. Even with the treatment, i.e. the transfusions, I still feel a lot of fatigue, particularly a week before and a week after transfusion, I can still function but if I exert myself I can feel it.

52. As a thalassaemic one of the issues is that the pituitary gland is affected. I have been on testosterone replacement since I was a teenager and I am dependent on the hormone replacement injection. My wife and I are currently trying to have a baby, so I have gone from testosterone replacement every 3 weeks, to receiving two injections 3 times a week.

53. I wish to remain anonymous with regards to this statement, in the field that I work in I would not want someone to Google my name and establish that I have had Hepatitis C. Only my name needs to be redacted, as I do not believe that anything else will identify me.

Statement of Truth

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

Signed GRO-B

Dated 18/11/2020