

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1158001

Exhibit: WITN1158002

Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B I live alone at GRO-B I am currently unemployed.
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.
3. I have no contact with my maternal side of the family and I do not know their medical history.
4. I was diagnosed with Haemophilia B also known as Christmas disease (Factor IX level less than 1%) in GRO-B when I was GRO-B years old. I had a lot of bruises as a young child.
5. I spent a lot of time in the social system because people believed I was being abused. I was adopted at the age of GRO-B and went to live in GRO-B I

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returned to the [GRO-B] I then lived at [GRO-B]
[GRO-B] at the age of [GRO-B] until I was [GRO-B]
My [GRO-B] later adopted me, and I refer to my [GRO-B] as my mum and dad.

6. I was under the care of Liverpool Royal Infirmary (LRI), Royal Manchester Children's Hospital (RMCH) and Manchester Royal Infirmary (MRI).

Section 2. How infected

7. As a young child, I had a lot of blood transfusions and I was given Factor IX (FIX). By the age of [GRO-B] I was administering Factor IX (FIX) myself at home. I was trained how to administer FIX by the doctors and nurses at the MRI and at this point I had stopped receiving blood transfusions. I was also treated with FIX at school.
8. I would receive FIX on a weekly basis at school and I would treat bleeds with FIX myself as and when they occurred.
9. Based on the National Haemophilia Database records (NHD), a copy which is exhibited at **WITN1158002**, it shows that I was infected with HIV between 1983 and 1984. I was told in the late 1980s or early 1990s that I had Hepatitis C (Hep C).
10. I was given no advice regarding the risks involved of infected blood products. I knew that FIX was made from human blood products but no other information was provided about the risks involved. I was told that the treatment was a step in the right direction and it would give me a better quality of life.
11. In or about 1984 when I was approximately [GRO-B] years old I received a letter from the MRI stating that my whole family and girlfriend had to attend the hospital to have blood tests. From memory the letter stated that they were

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looking for something specific (maybe antibodies) but there was no mention that we would be tested for HIV.

12. My family's blood test results were negative. My girlfriend at the time also tested negative, which was a relief. I recall receiving a letter with a few paragraphs stating that I had tested positive for antibodies and I did not know what 'antibodies' was. I did not have a follow-up consultation with the doctors in relation to the letter. I always had routine blood tests in relation to haemophilia and therefore did not think anything of it. Reading the letter felt like they were talking about someone else and I did not really believe it was about me.
13. I recall the word AIDs was all over the media. It did cross my mind that the letter I received was about AIDs, however, because I did not have a consultation and no information was given I did not think anything of it.
14. I believe I was not given adequate information to help me understand and manage the infection. I consider information about HIV should have been provided earlier. I would have preferred a one to one consultation with a doctor instead of receiving a letter through the post, which did not mean anything. It was in the mid-1980s that I had my first consultation after receiving the above letter with a doctor, and it was confirmed that I was HIV positive. I do not recall any information given at the time, but I do not think the doctors had much information to give me. I believe I got most of the information from the television, adverts etc. I do recall receiving an odd pamphlet or little booklet about HIV, but nothing of much importance.
15. I believe the tests should have been communicated to me a lot earlier.
16. In relation to the advice given about infecting others, I was only told to wear a condom as it could be sexually transmitted. There was a lot of scaremongering and it was quite aggressive.

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17. I kept thinking to myself that it was only a matter of time before the infection would kill me.

18. In or about the late 1980s or early 1990s, I had a routine appointment (routine appointments were every 3 months), which I thought was for my haemophilia. I was then informed by the doctors in a very casual way "by the way you have Hepatitis C (Hep C)". I was given no information about Hep C or told how to manage it. I was not told about risks involved with Hep C. I consider the doctors could have been a little bit more organised and it seemed as though they did not know what to tell people or whether they should tell people at all. All I was told was not to drink alcohol.

Section 3. Other Infections

19. I recall receiving a letter in relation to vCJD stating that because I was exposed to the blood products, I could be at risk from vCJD. I received no other information about this. I thought that this was something else for me to think about and worry about. I did not know that I was being assessed for this or that this would have anything to do with me.

Section 4. Consent

20. I believe I was tested without my knowledge in relation to HIV and Hep C. I believe I was not provided with adequate information about the risks involved with HIV and Hep C and how dangerous the infections could be. I believe I was also treated and tested without consent and treated and tested for the purposes of research.

Section 5. Impact of the Infection

21. I feel that I am always emotional. I feel the infections have impacted me on every part of my life. I have not slept properly for 30 years and I still continue to have difficulties sleeping. I also get the blues every now and again, where I feel really low.

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22. I started to get other viruses and infections, such as thrush, cold sores etc after I was infected with HIV. I can attribute these smaller infections to HIV.
23. Word had spread that it was possible that I was infected with HIV and I felt that I was ostracised. I was unable to tell anybody that I had HIV and found it very difficult to speak to people about it.
24. The stigma was slightly different because I associated myself with having haemophilia. I did not ignore that I had the infections, but I really tried to block it out. Initially I thought it was happening to someone else and therefore did not take any notice of it.
25. In or about the 1990s I went travelling. I wanted to get away from the UK. When I was abroad nobody knew me or knew about my infections and I felt that I was able to live a normal life. I did not have to explain myself to anyone and I was just a person travelling from the UK. I believed running away was a way for me to cope. When I returned to the UK I went to college and did a 2 year GRO-B However, I did think to myself 'what's the point of having an education' as no one would employ me because of my infections.
26. When I returned to the UK it started affecting me more and more and I became very secretive and felt very isolated. I started recreational drugs and I started drinking a lot. I smoked a lot of marijuana and spent many years in a daze.
27. I do recall receiving a payment in the sum of £48,000. Unfortunately, I cannot remember when I received it or who I received it from. I used that money on alcohol and recreational drugs, as I did not want to think about the infections.
28. In or about the mid 1990s I thought I needed to get myself together. I started a new course and studied GRO-B Again I felt I was in the same situation

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as before that I would not get employed because of my infections. I also did not want to tell any employer that I was HIV and Hep C positive.

29. In or about the early 2000s I got some money from a Trust and put the money towards a mortgage. During the early 2000s, I had been suffering with depression and had been to the doctors to discuss my low mood. I thought that it would be a good idea to use this money to be proactive and make a positive change in my life. Since then I have had some responsibilities and try and stay positive in everything that I do, although it was not always easy.

30. In relation to physical effects from Hep C, I had an enlarged liver and did not develop Fibrosis or Cirrhosis. I do not drink now. However, when I was drinking previously it was only because I did not have enough information in relation to Hep C and I want to try and forget about the infections.

31. In or about the 2000s I was told that there was treatment (Interferon and Ribavirin) available and that I should start it. I was given information about the possible side effects from the treatment, but I did not know how severe it would be. I became suicidal and had to come off the treatment after 3 or 4 months. The treatment was horrible it crippled me physically and mentally. I had chronic fatigue. My appetite was affected and I lost weight. My bones ached and I constantly had headaches. I had nauseous and dizzy spells from the treatment. I felt that I could not live a normal day to day life when I was having the treatment. I was taking anti-depressants because of the treatment. After the treatment finished I was told that it did not work. I did not have a second course of treatment because of the side-effects that I suffered from the first treatment. I was scared to take any medication.

32. I have recently been offered Zepatier for Hep C and I was told by the doctors that it is easy on the body and has a 98% success rate. I did not start this treatment because of the side-effects from the first treatment, but having done my own research I will start it when I return to the UK from my holiday in the New Year.

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33. In or about the mid 1990s I was offered AZT treatment for HIV, but I did not accept it at first because I thought I did not need it. I was required to take a lot of pills and I knew from doing my own research that the medication would be harsh. However, when I started the treatment I did not really have any side-effects. After having the treatment I was told that my results had improved and I was below the level of detection. I am now taking one tablet a day.
34. At one point my blood count levels went up slightly, but I adhere to my strict regime of medication. I used to attend the hospital every 3 months to have my blood tests, but now I attend every 6 months. I do feel angry about the situation but I have now learnt to deal with it.
35. I used to feel very anxious when I attended the hospital for my routine appointments. I always thought "today is the day that they are going to tell me that I am in trouble". Sometimes I feel very lucky compared to others. Other days I say to myself 'why me?'
36. I have had a few long-term relationships. Being in a relationship has impacted me massively because I cannot have children and start a family. I found it difficult to talk to people about the infections, because it was daunting and scary. I was in a relationship when I was having treatment for Hep C, but I had to end the it because I could not commit to it. GRO-B
GRO-B so it was a difficult time for me and I was suffering from depression. I did start a relationship again a year later, but a conversation about children came up and I had to end the relationship.
37. I have lost friends because I told them about the infections. I became very paranoid because I felt that everyone knew about my condition.
38. In relation to employment, I believe that I would not have been employed because of my infections. I did not want to explain at the interviews that I was infected with HIV and Hep C. I was very reluctant at the time. I never really started work or committed to it, because I thought the infections would kill me.

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When I watched the news I found out that people who were infected with HIV and Hep C had a very limited lifespan. I did do some cash in hand jobs for friends to help pay for bills.

39. I wanted to be a but I felt that I was unable to pursue a career in this because of my infections.

40. When I see my parents I try and stay positive about my situation. I do not show that I am having a bad day. I felt that my brother was unable to deal with it.

41. I have been in a relationship for the past years and we are getting married next year. I have a and they are both aware of my situation.

Section 6. Treatment/care/support

42. I believe I was offered some care and support when I was having treatment for Hep C, but I did not accept it. I was not offered any support when I was diagnosed with the infections and I believe it would have helped had I been offered it at the time.

43. I am aware that people are being offered counselling and support, but I have not been offered it.

Section 7. Financial Assistance

44. In or about 1991 a letter was posted to me stating that I was entitled to some money. I received two lots of payments, £21,000 and £28,000, ex gratia payments. I believe that I was giving up rights to sue at a later stage.

45. As previously stated at paragraph 29 I received a lump sum payment of £48,000, but I cannot remember who I received it from.

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46. I also received a payment from the Skipton Fund. I just received a letter through the post stating that I was entitled to £20,000 because I had Hep C. I filled in the form and sent it back.
47. I did not apply for any grants. I took care of myself. I did not have a computer and it was very strategic applying. I found it difficult to apply and thought it was confusing.
48. I receive monthly payments from Macfarlane Trust (now EBISS). The payments were pitiful initially; I was only receiving approximately £130 a month. The monthly payments have gone up slowly over the years. It was difficult to apply for the above monthly payments and had to provide a lot of information. I did not think there was a point because they were asking for a lot of information.
49. I now receive a payment from EIBSS. I hate seeing the name on my bank statement. I received approximately £23,000/£24,000 (per year). However, I was told that if I have a dual infection then I can also apply for special category mechanism, which amounts to a further £18,000. The total that I therefore receive is approximately £40,000 a year. I hate applying for the above payments, as I find it very degrading. I have to apply for a discretionary top up payment every year in April and they require a lot of information and proof. I consider applying for the payments should be the same as all the other countries that have been affected (France, Italy, Spain, Japan). I do question why it has taken the UK a long time to deal with it. In other countries people have been sent to prison over this and we have only started to do something about it.
50. I consider the payments should be a lump sum basis and not monthly payments.
51. I did not initially make a further application in relation to Hep C as I did not think it applied to me. I only applied last year and did not apply to have the payments backdated. I do not consider the money I get it enough.

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52. Macfarlane Trust had a consultation with everyone about how to move forward. I got involved in this consultation and gave my thoughts online, but they were ignored.

Section 8. Other Issues

53. I do not think I should have a financial or medical assessment for the payments. I understand that they cannot just hand over the money, but I feel degraded.

54. The money that I received was never enough to be comfortable. I was only having to support myself and I do not consider I would have been able to support a family.

Anonymity, disclosure and redaction

55. I confirm that I do wish to apply for anonymity.

Statement of Truth

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

Signed

GRO-B

Dated

24/12/2018

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Medical Summary

(This summary is not intended to exhaustive but sets out key points in the records relevant to the statement)

Virology Results

All blood tests records are missing

Significant Entries/Absent Entries

- 10/1974 Summary Sheet (RMCH) from Dr GRO-B – 'the diagnosis was made in 1966 when he was two years old....
In the past his bleeding has been treated with frozen plasma, but recently we have been able to use a Factor IX Concentrate.....
Tests for Australia Antigen were negative in January 1973 but has not been repeated since then'
- 6/03/1981 Summary Sheet (RMCH) from Dr GRO-B – History of left sided abdominal pain which had come on whilst he was at work..... a provisional diagnosis of bleeding into the left psoas was made. He was given an injection of factor IX concentrate and appeared to settle. Later on in the evening his pain recurred after a further injection of Factor IX he settled..... but on the next day the testis was much more swollen and a surgical opinion was obtained. A diagnosis of acute testicular torsion was made and surgery was carried out that afternoon under cover of factor IX concentrate..... he was given twice daily Factor IX injections for the rest of his stay and was allowed home on the 14 March with instructions to give.
- 30/12/1984 Discharge summary: Diagnosis: Gastro-intestinal bleeding due to duodenal ulcer.

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Management: treated with large doses of FIX and received six units of blood transfusion.

- 06/07/1985 Letter to Dr **GRO-B** from named crossed out – this patient with severe haemophilia B has recently been shown to be anti HTLV 3 antibody positive. As there have been numerous sexual contacts in the past 5 years it will be necessary for us to find out when seroconversion took place by testing back samples, before knowing which of his sexual partners are actually at risk and will need blood tests.
- 16/03/1988 Letter to Dr **GRO-B** from Dr **GRO-B** – presented after vomiting approximately 1 ½ pints of fresh blood and ½ pint of melaena. he recovered quickly with intravenous fluids and IX
- 24/06/1993 Letter to Dr **GRO-B** from **GRO-B** – I am writing to inform you of the following blood test results obtain on your patient.
Hep A – patient is not immune to this infection. As there is a slight risk of contracting Hep A from blood products
Hep B – patient has had infection with Hep B in the past and is now immune
Hep C – patient is Hep C positive by a second generation test
Liver enzyme results on your patient are normal but have shown elevation in the past, compatible with hepatitis infection.
- 05/06/2009 depression resolved discontinued interferon and ribavirin – off anti-depressants.