

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1465001

Exhibits: 0

Dated: 1st 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 the GRO-B and I live at GRO-B where I live with my wife and our GRO-B I am currently GRO-B due to my ill health.
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.

Section 2. How Infected

3. I was diagnosed with Haemophillia A (which is moderate to severe) during the examination of my GRO-B I was GRO-B GRO-B I had my first treatment with blood products (Factor VIII) for the operation to

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my [GRO-B]. I have received further blood products between [GRO-B] which came from various companies.

4. I also received blood products from the age of [GRO-B] throughout my life, however, the period between [GRO-B] is the only period which has been properly documented in my medical records. My medical records also include some information about the products used between [GRO-B]
5. I have been registered at the [GRO-B] Hospital for the past 20 years (from about 1995), however, I was originally registered at the [GRO-B] Hospital.
6. A lot of my medical information is missing, as ever since I was born, I have been moved between different hospitals. As I was [GRO-B] I was moved from the hospital where I was born, to [GRO-B] unit in another hospital. I was then adopted, so I was moved to another hospital again. I was then moved between a couple of hospitals later in life.
7. My Haemophilia care, which I received until [GRO-B]
[GRO-B] was also the main person who administered Factor VIII to me.
8. I have questioned my mother whether my parents were ever informed about the risks associated with being administered blood products. She stated that she does not recall any such information being given to them at any point.
9. I have been infected with HIV and HCV as a result of being treated with blood products.
10. As there have been many occasions when I have received blood products, it is impossible to state when I was infected with HIV and HCV.

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11. Neither I, nor my parents were ever informed that I was tested for HIV or HCV. I had regular blood tests every few months and it was always believed that it was nothing out of ordinary, and that they were required to monitor my Haemophilia.
12. I recall I was asked to attend hospital, I assumed it was for a routine blood check-up or review. At the time I was under the care of Dr Dudley at the **GRO-B** Hospital, who took over **GRO-B** This is when I was informed by Dr Dudley that unfortunately I had been infected with HIV through a bad batch of Factor VIII.
13. It was a very unpleasant conversation and Dr Dudley did not provide the information in a good manner. I believe I was told of the infection at that time as I had reached the age of consent and he knew I was becoming unwell, further I believe he knew too that the HCV was affecting me.
14. I have reason to believe that my doctors knew about the fact that I had been infected with HIV long before informing me.
15. Further, as a result of reading my medical notes I believe that **GRO-B** **GRO-B** might have been aware of my HIV infection, and the doctors had been trying to convince her to tell me about it, however she never did. I assume that she wanted to protect me by not telling me.
16. I do not recall being given any information about HIV, such as a fact sheet or information about how it could be spread. I might have been given a piece of paper containing information, however I was not told of the consequences. At the time, the only information I had (based on what I had heard before) was that HIV was associated with drug users and gay people.
17. I was offered counselling straight away. I was also told that I should receive medication as soon as possible, however, I delayed the treatment as much as I

could until the antiretrovirals were made available to me in, I believe, around

GRO-B

18. Within a year from being told about my HIV status I suffered my first bout of pneumonia. In the intervening years I have had pneumonia five times and TB once.

19. Dealing with Dr Dudley sealed my decision to leave GRO-B for GRO-B

GRO-B It was also a much bigger hospital, compared to GRO-B so it seemed to be the right decision.

20. I found out I had been infected with HCV some time after finding out about my HIV status. I recall overhearing it being mentioned in the Haemophilia circles. Therefore about GRO-B I asked GRO-B whilst in the busy reception area of GRO-B She told me not to worry about it, as it had cleared spontaneously a long time ago and that I did not need to take any drugs for it. I was never informed about the infection officially. Thankfully it has not caused any damage to my liver.

Section 3. Other Infections

21. I recall receiving a letter from the Hospital stating I may have been exposed to CJD.

Section 4. Consent

22. I was never informed that I was having any tests to check whether I was infected with any viruses. Neither I, nor my parents knew about the HIV or HCV tests, which were performed on me. We never questioned the need for the blood tests as we assumed they were to monitor my Haemophilia. Therefore, consent was never provided for any of those tests.

23. I was never made aware that any tests were being done for the purpose of research, though I assume that there were some tests done for that purpose.

Section 5. Impact

24. When I first found out that I had been infected with HIV it was a massive shock for me and I found it very difficult to cope with. As mentioned earlier, the only information that I came across before related to contracting HIV was negative, relating to things such as drug abuse, and that was not something that I wanted to be associated with.

25. HIV had a huge negative effect on my education and career. I was told about my infection around the time when I was studying for my GCSEs. I therefore found it impossible to concentrate on normal school life.

26. Also not long after being told about the HIV infection I was involved in two incidents which caused me to have bouts of pneumonia. In the first incident I was

GRO-B

and in the second incident I was

GRO-B

GRO-B

The pneumonia has caused a serious scarring to my lungs.

27. The pneumonia caused me to have a lot of time off school, which led me not to be able to sit my GCSE exams, as I was unable to study. Therefore I did not finish my GCSEs. I just have a certificate stating I attended the school for 5 years, but I have no official qualifications.

28. I was very active while I was at school, I worked as a shelf filler at

GRO-B

and I also did

GRO-B

However when I was told of the infection I had to give up those jobs due to my illness as I was in and out of a hospital for the following five years so I was not able to return to work.

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29. I never had the chance to explore what I enjoy, in terms of education and career path, because I have missed out on trying things in school. I believe that if I was given the chance to finish my GCSEs and continue my education, I would have had a good chance to build a career and to potentially be in a much better financial situation throughout my life. I find it particularly upsetting to see that my younger brother has been able to build his career as a **GRO-B** and I never had the chance to try. Though I am obviously pleased for him.
30. Also not only was I unable to continue my education and build a successful career, I am also not physically able to sustain a job, because of the chronic fatigue caused by HIV.
31. Over the years, I have undertaken small unpaid tasks for family and close friends for something to do and to help others. However, this has taken such a toll on my body that I kept on ending up with bleeds or severe fatigue.
32. Some of my friends have provided me with smaller tasks, which were not as harsh on my body, such as running errands; however I was not able to do that for long, as I get extremely fatigued very quickly.
33. After discovering I was infected with HIV I was offered counselling, during which I was diagnosed as clinically depressed and as a result I have been on and off medication to help me to cope with it ever since.
34. At present I do not get any help with my depression. At the moment I am feeling ok, it ebbs and flows. I still get periods, when I am particularly down, and I find it extremely hard to cope with. It is impossible to just snap out of it, it takes time.
35. At one point, a psychologist at **GRO-B** recommended I see a psychiatrist through my GP with the view to being prescribed medication, however my GP

thought that I did not require the referral which was frustrating. My GP did though prescribe anti depression medication to me any way.

36. I also recall reading the small print on the packaging for one prescription I was given for medication for depression, which stated that it may increase the chance of epileptic fits. This medication was entirely inappropriate for me as my **GRO-B** suffers from severe epilepsy and I have had a couple of **GRO-B** one on the **GRO-B** and another one **GRO-B** earlier. I therefore stopped taking the medication.

37. Being told by my clinical nurse that I had contracted HCV also affected me. Whilst I was told I am clear of it and that I should not worry about it this did not put me at ease. I have seen friends who had been on long and hard treatment programmes, and knowing that the HCV could return makes me anxious.

38. I also suffer from gout and tophus. I have been suffering from them for the last **GRO-B** years, and I find it very debilitating, as it has deforms my toes. I believe that this occurs when gout and HIV push up the steroid levels in my blood.

39. I also suffer from Lipodystrophy, which causes fat dispersal to be uneven. In my case it causes lumps of fat in my abdomen, this could have been caused by the drugs used to treat my pneumonia.

40. Some of the treatment I receive has had adverse effects which I am living with now. One drug in particular started causing my eyes to blur, whereas other drugs caused my cholesterol levels to rise, and I now need to take other drugs in order to combat it.

41. I have also had neuropathy in my feet in the late 90s, which was very painful, and I was not able to walk as my feet were so sore and so sensitive. My stomach has

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also been constantly upset. I have also a lot of muscle wastage, muscle aches and chronic fatigue.

42. My HIV infection has also affected my social and family life. My wife knows about my infection, GRO-B I

have always struggled to meet women due to my lip and haemophilia and due to my HIV status therefore I didn't have the opportunity to have experiences with women as a teenager.

43. I am a naturally shy person, however, due to my HIV status I have become even more isolated. I have stayed away from women as I was scared of being rejected once they found out about my infection, or that they would accept it and I would die at any time.

44. I have a GRO-B who knows about my Haemophilia, however I keep my HIV status as a secret as in particular I am afraid that if my status was revealed she would be bullied at school.

45. I have had to keep my HIV status a secret from my family, particularly my wife's side of the family. My wife's family does not know about GRO-B HIV positive. This causes a lot of awkward and stressful situations for my wife and I during various family events. This is added to as my wife's mother follows various media outlets relating to Haemophilia patients, therefore she tends to ask a lot of questions.

46. We believe that if my wife's parents found out about my status, it would cause a lot of problems. Her mother was sceptical towards me when she found out that I was a Haemophiliac in any event.

47. We have also decided not to let our friends know about our status, due to the stigma attached to it. This causes us to feel rather isolated in the social setting. It

also causes me to feel constantly on guard. We tend to stay away from meeting new and sometimes old friends as it is too stressful.

48. The secrecy proves to be particularly problematic in social settings, especially when people ask me what I do for living and the reason why I do not work. I feel I have a lot of secrets, which weights heavily on me, as I feel it makes me look like a fake, because I look too healthy and have survived whereas I am very unwell. It is very cloak and dagger. For example I have a mobility car but have not revealed to friends and family that I have assistance because of the questions this would raise.

Section 6. Treatment/Care/Support

49. My mother recalls that when I was about GRO-B years old GRO-B Hospital refused to treat me. She took me to the hospital for treatment for my Haemophilia but I was refused access for fear of cross contamination due to my HIV status. As a result I was sent to a hospital in Hither Green where I was treated in a private room. My mother recalls this was the worse time in her life because I was refused treatment.

50. I am not sure whether more could have been done at the time, in terms of treatment. I think it is fair to say that there was no proper HIV treatment available at the time and the doctors were probably treating me with what they had at the time.

51. I have now been on the current regime for the past 3 years, however my doctor is planning to change it to something, that he says is better for my kidneys. I am concerned that the reason for the change is to save money and also I am worried about the transition period.

Section 7. Financial Assistance

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52. I have received financial assistance from the Macfarlane Trust. When I was GRO-B years old, my GRO-B explained to me that after what had happened to me the Government had given me money and it has been put on trust till I turned 18.

53. I then went to see a solicitor who was holding the money for me and I was given a cheque from the Trust.

54. I believe that my trust has been put into place in 1991, and I received the money in about 1996. The amount I received was around £21,500.

55. I have also received money from the Skipton Fund. I do not recall how I found out about the Skipton Fund, but I believe it might have been a word of mouth. I cannot recall the exact date when I received it, but it was around £20,000. I received various amounts of money from the fund from around 1995, I recall that they were quite low in the beginning.

56. I now receive funds from EIBSS on monthly basis, as well as a monthly top-up payments which are means tested.

57. I find the process of application rather tedious as I am required to provide a lot of information such as incomings, outgoings, such as the bills, monthly spending on clothes. This also includes my wife's income, making it a very long process.

58. The only pre-conditions imposed on the application process was to provide my medical records and to provide all the financial information necessary as well as two quotes for any item being financed.

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59. Overall, I have not applied for many grants because the tedious process of application has put me off. This is also to prevent the disappointment of going through a long process and not being able to get the money in the end.

Anonymity, disclosure and redaction

60. I confirm that I do wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

61. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed.....

GRO-B

GRO-B

Dated

1st

November 2018
December

MEDICAL SUMMARY

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

GRO-B

Transferred for repair to GRO-B

Report, GRO-B During an examination of his GRO-B

GRO-B it was discovered he is haemophiliac.

Letter, GRO-B

GRO-B had to be postponed

because he was found to be suffering from moderate to severe haemophilia.

Factor VIII Investigation of Blood Coagulation: Factor VIII antigen 125%

Consent from parent for GRO-B to have operation by no mention of risks from blood products.

Admitted for correction of GRO-B Will have appropriate FVIII

Factor VIII

Pre-op. factor VIII

Factor VIII given

Factor VIII given

Factor VIII given

Child will need a IV line for factor VIII.. and after operation on GRO-B

...a blood test for GRO-B to test his haemophilia and ? antibodies

Dental GRO-B needed Factor VIII

Fell on GRO-B cut to scalp. Factor VIII conc 269 x 2.

Further (260 x 2) units of Factor VIII

No irregular antibodies found

Patient has had Factor VIII

Result from Colindale HTLV-3 +ve

Fell GRO-B Factor VII given

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Paediatricians worried about risk of infection (HTLV IV)
 Factor VIII given
 File note: GRO-B is a GRO-B year old haemophilia who has been having
 GRO-B on and off for 5 weeks. Treatment with Factor VIII
 has not helped. About 18 months ago he had the same problem... he
 was treated with tranexamic acid.
 Given 190 x 4 Elstree Factor VIII
 Letter, GRO-B Dapt of Haematology to GRO-B
 The injury was treated by twice daily injections of factor VIII
 concentrate
 Result from GRO-B - 3 positive
 He is HTLV III positive
 Letter GRO-B Has
 an onychogryphosis of the right big toenail. This was removed in
 1984 but has recurred. ... needs removal ... with full factor 8 cover....
 Hepatitis C antibody test - negative
 Hospital Note: GRO-B becoming unwell after factor VIII
 infection. History: 11.00 had factor VIII for home bleed. 12.45 felt
 unwell.
 Hepatitis C antibody Positive
 Factor VIII 2,500 u given into left cubitas
 Factor VIII 1,560 u given
 Factor VIII given x 2
 Letter from GRO-B Children's Hospital
 GRO-B Admitted 10 to 13.04 GRO-B still doesn't know he
 has HIV the matter has been discussed with GRO-B family and the
 Haematology team.
 DW Mother need to inform of HIV status at next visit. HIV counsellor
 to be present.
 Now given FVIII x 500. Last CD "227" (CD4 1084 2/12 previously)
 Patient informed of HIV status and significance. Appointment with

	HIV counsellor followed immediately.
	Fell off bike this a.m. (08.30)
	Hep C HIV
	Haemophilia Review. Hep C pos.
	Admitted, GRO-B of left big toe nail and nail bed.
	Known Haemophiliac A, HIV (+ve)
	Hepatitis C antibody – positive
	Factor VIII given
	Having factor VIII Rx
	Knocked off bike admitted
GRO-B	Intermittently takes factor VIII when he bleeds into joint (usually ankle or knee) – Factor VIII approx. once every 2-3/52. More Factor VIII today.
	GRO-B is HIV +
	Admitted for nose bleed, started yesterday. Factor VIII given
	Factor VIII given
	Re-admitted for blood transfusion
	Admitted - fitting
	CD4 > 200 Dapsone and AZT Does not want any more tablets
	PCR positive
	Hepatitis C antibody = positive
	Hepatitis C detected