

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1322001

Exhibits:0

Dated: November 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 and I currently reside at GRO-B GRO-B
2. I was infected with Hepatitis B, Hepatitis C and HIV as a result of receiving contaminated blood products.
3. 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.
4. Where dates are referred to in this statement and I have not had access to my medical records those dates are recorded to the best of my knowledge given the passage of time.

## ANONYMOUS

5. When I made enquiries with Leicester Royal Infirmary I was informed that my records had been destroyed and that it was the hospital's policy to burn them after a specific number of years. I asked them why not all my records had been destroyed (as I was provided with some records after 1996) but they did not have an answer.

### Section 2: How Infected

6. I was diagnosed with severe Haemophilia A when I was about 2 years old and I spent a lot of my early life in hospital having on demand treatment. I was initially treated at Leicester General Hospital and transferred to Leicester Royal Infirmary (LRI) under Dr Vivien Mitchell (Consultant Haematologist) when I was 15. I was treated there until about 2000 when I moved to the **GRO-B** area and my care was transferred to the Haemophilia Centre at the Royal Free Hospital in London.
7. When I was first moved onto Factor VIII it was sold to me as some kind of wonder drug. I was told that it was a real breakthrough and that soon I would be administering it myself. The first time I received Factor VIII I went to hospital expecting to be put on cryoprecipitate but they administered Factor VIII instead and very quickly told me I could go home. I was given the Factor VIII with no information, advice or warning of any risks. I was not told that I had been received different treatment until after the Factor VIII had been administered when I asked why I was able to leave the hospital much sooner than usual following my treatment.
8. I first started having home treatment around 1979. In the early days of my home treatment we were not given any treatment records by the hospital to record what treatment had been used when or for what. At the time of writing this statement I have not had access to my UK Haemophilia Database records.
9. My Dad would sometimes administer my factor and he occasionally pricked himself with the needle by accident. This came up in conversation with my

## ANONYMOUS

treating doctor and they ran some blood tests on him which confirmed that he had Hepatitis B. I believe this was in or about 1980.

10. I believe I was first tested for HIV in or about 1984.

11. In or about 1985 Dr Mitchell called me in and informed me of my diagnosis of HIV. The consultation was very matter-of-fact and I felt that Dr Mitchell's delivery was poor and insensitive given all the circumstances.

12. This was around the time of the HIV media campaign from the Government, and I was very worried about my diagnosis. Dr Mitchell did not provide me with any real information about the disease or the routes of transmission when I was advised of my diagnosis. I remember being scared.

13. LRI later invited a large group of those who had been infected to a group meeting. In this meeting they told us a little bit more HIV, and said we should stop 'some of the things we were doing'. It was basically a lecture on safe sex/transmission. It was almost like a lecture from a prudish teacher and they couldn't be bothered to tell us this information on a one-to-one, personal basis. At that meeting Dr Mitchell said openly that the infection had been caused by contaminated blood products. I already suspected as much because of some of the things I had seen in the media.

14. The care I received under Dr Mitchell and Carol Martin (the sister on the ward) in the haemophilia department was questionable to say the least. I recall on

GRO-A

GRO-A

15. Shortly after my diagnosis with HIV Dr Mitchell suggested that my then girlfriend should be tested as well. A few weeks after the test I went for an appointment and Carol Martin told me that my girlfriend had tested HIV negative. She asked me to pass the news on to her. I found this extremely

## ANONYMOUS

unprofessional and it undoubtedly broke confidentially rules. I was amazed that it appeared they couldn't be bothered to tell her themselves.

16. After my diagnosis with HIV I went to work abroad as a DJ in the Canary Islands. I cleared this with Dr Mitchell and agreed that I would take Factor VIII with me and return every few months to get more factor.
17. It was when I came back for a routine appointment that I was told I was Hepatitis C positive. I believe this was sometime in the early 1990s. By then I had already been infected with Hepatitis A and Hepatitis B because I remember Dr Mitchell saying "you've had the lot" when he told me of my new diagnosis. I believe I cleared Hepatitis A and B naturally.
18. Dr Mitchell again provided very little information about the infection.
19. I recall on one occasion in the mid 1990's I was given Factor IX instead of Factor VIII to take home and treat myself with. The packaging looked exactly the same as Factor VIII, which meant I was treating myself with the wrong product and left wondering why it wasn't working. When I raised this with Carol Martin she tried to blame me for not checking the bottles closely enough.
20. It was shortly after this that I decided to transfer my HIV care to the Infectious Diseases department of Leicester Hospital, due to the poor care I had been receiving in the haemophilia department; I knew Dr Mitchell and Carol Martin did not like the fact that I transferred. I remember seeing Dr Mitchell after the change and he said "are you still here?".
21. Following the transfer of my care my treating doctors quickly recommended I take the anti-viral treatment that Dr Mitchell had advised against. I started to feel a bit better after taking this medication. I had previously also sought the advice from a nurse I had befriended in hospital in Newcastle, as I didn't trust the haemophilia department at LRI.

## ANONYMOUS

22. Although I have never received any information as to exactly when I was infected via contaminated blood products I have always believed that I was infected by Cutter Koate as this is the product that I remember using a lot when I was administering home treatment in the late 70s/early 80s.

### **Section 3: Other Infections**

23. I have also previously been diagnosed with Hepatitis A and B. I believe I have cleared these naturally, but have been told very little regarding the infections. I believe I was tested after they tested my father and found he was Hepatitis B positive.

24. On a date that I cannot recall Dr Mitchell called me in to see him and told me that I was at risk of vCJD. I cannot recall receiving much/any information about this although I may have received a couple of general letters about the risk over the years.

### **Section 4: Consent**

25. I cannot recall if I was told I was tested for HIV because of the passage of time.

26. I do not believe that I was told or that I consented to testing for Hepatitis A, B or C.

27. I also do not recall being asked to consent to the resistance assay testing on my stored samples which took place in 2002.

### **Section 5: Impact**

28. There wasn't really any support available when I was at LRI. The process of my girlfriend's HIV test was extremely difficult for both of us and ultimately led to the end of our relationship.

## ANONYMOUS

29. I have struggled to form new relationships since then because it is so difficult talking to new people about my infection, especially potential partners.
30. I haven't suffered from the stigma of the infection too much from the public as I only really tell people who I know and trust. However, I have been treated poorly by some medical professionals due to my infection.
31. In 1994 I needed a knee replacement. The surgeon GRO-D refused to operate on me because he was worried about my infection. He said he would just straighten it instead. In the end I requested a second opinion had to go 200 miles away to Newcastle where they were happy to operate.
32. On another occasion I recall a doctor dressing up in something that looked like a spacesuit to help remove an ingrown toenail.
33. After my knee surgery I spent a few years doing odd bits of music work, before moving to Outer London. I had a friend who offered me a job in his music studio and I was eager to move to a different hospital, so I moved.
34. In or around 1996 I started to feel very lethargic and ill. It was having an impact on my life and my work and I had to really motivate myself to do anything. I was physically very weak.
35. After moving to the Royal Free, Professor Johnston started to alter the mixture of my anti-viral treatment and it wasn't until she had perfected the dose that I started to feel better again.
36. In 2003 I started treatment with Interferon, which successfully cleared the Hepatitis C virus. It was only after I transferred my care to the Royal Free that I was fully advised about the possibility of Interferon treatment. I believe I was on this treatment for about 6 months. The treatment involved injecting myself in the stomach daily.

## ANONYMOUS

37. As a side effect of the treatment I lost a lot of weight. I wasn't able to eat because I felt nauseous all the time. It also caused my hair to fall out. I suffered from quite bad depression and had terrible mood swings. I still feel this way sometimes now even though the treatment was 15 years ago.
38. Fortunately, Barbara, the nurse at the Royal Free prepared me for the side effects of the Interferon treatment and helped me through it. Undergoing the treatment would have been much more difficult without her support.
39. I have consistently had problems with my knees and ankles over the years. In or around 2006 I slipped and broke my artificial knee. This took quite a while to heal so I moved back with my mum for a short while in Leicester. In the last few years I have had pins put into both ankles and work done on my knees. I have had to replace my knee again, although it took 2 years for the surgery to be done. I felt very low at points waiting for this surgery to take place.
40. In 2013 I had really bad depression and attempted suicide. Everything seemed to be going wrong in my life. I felt ill, I was suffering from fatigue and I couldn't work. My knee was also bad and I was in pain. I took some pills and tried to overdose. I didn't want to be found but somehow someone did find me and took me to University College London Hospital where they saved my life.
41. When the Royal Free found out about this they were extremely nice and reassuring. I have always been very impressed with and grateful for the care I have received from the Royal Free, which is in stark contrast to the care I received at Leicester General Hospital.
42. Some days I still feel extremely lethargic. I suffer from fatigue and I can't put my finger on the reason. I am usually a happy-go-lucky guy so it is tough when I feel down and fatigued.
43. It was very difficult for my mum to cope when I first informed her about my diagnosis; however she has since come to terms with it and learnt to accept it.

44. I am currently in a housing association property and have never been able to get a mortgage or life insurance.

45. It is probably a combination of the haemophilia and HIV that means I am unable to work.

#### **Section 6: Treatment/Support/Care**

46. At Leicester I was never informed of any potential treatments for Hepatitis C and they advised me not to take the anti-viral drugs for my HIV. When I was in hospital on one occasion I was put on an AIDS ward and the doctor there advised me to take antivirals.

47. This changed at the Royal Free where they were much more supportive and informative, and provided me with the options that were available to me regarding treatment for both my HIV and Hepatitis C.

48. When I started my HIV care I was on triple therapy taking SAQ, AZT and Lamuvidine. I was taking being 9 and 12 tablets a day. I now just take 3: Darunavir, Tenofovir and Maraviroc.

49. When I was diagnosed with HIV Carol Martin bluntly told me that I could see a psychiatrist if I wanted. I decided that therapy was not for me and did not proceed with this. Again I felt the way that the offer of treatment was communicated was poor.

#### **Section 7: Financial Assistance**

50. I received the Stage 1 lump sum payment from the Skipton Fund and also received a lump sum from the MacFarlane Trust (the Trust). I cannot recall the dates or amounts due to the passage of time.



## ANONYMOUS

51. The Trust also gave me a £1000 business grant when I wanted to start a business with my brother-in-law. The application for funding that I submitted requested a grant of £3,000.
52. When my father was dying I asked the Trust for the money to go and visit him in North Michigan before he passed away. They asked me provide them with a quote for the flights and accommodation, which I priced at £1,500. They eventually gave me a £1,320 contribution. I found them extremely difficult to work with.
53. Before the Trust closed they wrote to everyone asking if anyone needed any home improvements as they still had money remaining. I was a bit annoyed that they had been so reluctant to fund my trip for me to visit my dying father but were now but now offering funding because they were closing and had so much money left they were just trying to spend it. I felt like they were sitting in nice offices, receiving a few calls a day and withholding money where possible.
54. I was glad when the Trust was dissolved. I know of several widows who had terrible experiences with it.
55. I currently receive PIP, housing benefits and severe disablement payments. I now also receive monthly payments from EIBSS.
56. I have also received assistance from Neil Bateman, the benefits advisor, at the EIBSS who helped me to complete my benefits form when I was taken off PIP.

### **Section 8: Other Issues**

57. I want to know why my medical records were burnt and I can only access them as far back as 1996. I don't understand why they would destroy the records of a person with such serious infections when they are still alive.



## ANONYMOUS

58. I also want to know why people were kept on Factor treatment when it was known that something was wrong with it, especially considering there was still the option of reverting back to Cryoprecipitate. If I had been informed of the risks of Factor VIII I would have gone back onto cryoprecipitate treatment.

### Anonymity

59. I confirm that I wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

60. I would be prepared give oral evidence at the Inquiry if the Inquiry felt it would be helpful

### Statement of Truth

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

GRO-B

Signed

Dated

28-11-2018



# ANONYMOUS

## MEDICAL SUMMARY

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

1994	Knee replacement.
10.01.1996	Leicester Royal Infirmary clinical notes. HIV +ve through "blood transfusion". Haemophilia A.
20.06.1996	Leicester Royal Infirmary notes. D/w haematologist – feel that anti viral therapy would be inappropriate at this stage.
31.07.1996	Virology. Additional report. Report from the Regional Virus Lab, Birmingham Heartlands Hospital. Hepatitis A antibody positive by ELISA. This patient is immune to Hepatitis A.
15.08.1996	Leicester Royal Infirmary notes. Please note he is <u>HIV +ve hep C +ve HIGH RISK</u>
22.05.1997	Leicestershire Pathology Service. HIV 1 RNA by PCR: NOT detected by PCR.
21.08.1997	Leicestershire Pathology Service. HIV 1 RNA by PCR: POSITIVE
27.11.1997	Leicestershire Pathology Service. HIV 1 RNA by PCR: NOT detected by PCR.
19.02.1998	Leicestershire Pathology Service. HIV 1 RNA by PCR: NOT detected by PCR.
14.05.1998	Leicestershire Pathology Service. HIV 1 RNA by PCR: NOT detected by PCR.

## ANONYMOUS

27.07.1998 Leicester Royal Infirmary clinical notes (Dr Mitchell). Chat with **GRO-B** at his request re HIV and long term prognosis for him. I explained that the treatment of HIV has improved and is continually improving all the time. The patients diagnosed during the latter ½ of the 80s have done much better than the early ones so I have reassured that there is no reason why **GRO-B** **GRO-B** should NOT get on with his life. This seemed acceptable to Mr **GRO-B**

13.08.1998 Leicestershire Pathology Service. HIV 1 RNA by PCR: NOT detected by PCR.

09.11.1998 Leicester Royal Infirmary clinical notes (Dr Mitchell). HIV, Hep C positive 1984 both via blood products.

12.11.1998 Leicestershire Pathology Service. HIV 1 RNA by PCR: NOT detected by PCR.

23.02.1999 Infectious disease unit out patient notes. Known haemophiliac on Factor 8. HIV + since 1985. Hep C + approx. 5-6 years ago. On triple therapy for at least 2 years. SAQ, AZT, Lamuvidine, Dapsone, F (Regular on Med). Feels well. No fever, cough, breathlessness. Good appetite, no difficulty in swallowing. No diarrhoea or vomiting. No skin problem. For FBC, biochemistry, CD4, viral load, Hep C RNA, HepBs Ag, toxoplasma antibody, CMV.

23.02.1999 Letter from Dr Herieka....He is a known haemophiliac on Factor VIII regularly. He has been HIV positive since 1985 and has been found to be hepatitis C positive for the last 5-6 years. He has been on triple therapy for the last 2 years.....

## ANONYMOUS

23.02.1999	Leicestershire Pathology Service. HIV 1 RNA by PCR: Positive
27.02.1999	Leicestershire Pathology Service. Hepatitis B surface antigen. Negative by EIA.
12.03.1999	Letter from Dr Mitchell (Haematologist). <b>GRO-B</b> was well when seen in the Haemophilia Centre for review. At his request he has been referred to Dr Wiselka for care of his HIV related problems.....He has been on triple therapy with AZT, Lamivudine and Sequinovir since August 1997. Viral load studies have shown HIV1 RNA to be undetectable by PCR in August and November. In view of this he has not been changed from Sequinovir to Nelfinovir for the time being. Generally he is very well with no symptoms.....
23.03.1999	Infectious disease unit out patient notes. HBsAg -ve, Hep C RNA awaited.... Explained tests satisfactory.
Undated	Letter from Dr Qureshi (Haematologist) to Dr Wiselka (Infectious Diseases). This 36 year old man with severe haemophilia A is HIV and Hepatitis C positive. His lowest CD4 count was recorded in August 1997....He was commenced on triple therapy with AZT, Lamivudine and Sequinovir, in addition to prophylactic dapsone on 10 September 1997 to which Itraconazole syrup in November 1997. This was later changed to fluconazole because of gastro-intestinal upset. There has been some improvement in the CD4 count and one HIV RNA was negative by PCR when last checked in August 1998. He is otherwise well and has not has any opportunistic infections. His weight remains stable. His liver is not enlarged clinically, but his ALT remains elevated at approximately 3 times the upper normal range. <b>GRO-B</b> has requested his HIV care be transferred to you....

## ANONYMOUS

23.03.1999 Letter from M Wiselka. He feels well and has had no problems since his last visit. His results are all satisfactory showing a CD4 count of 160, viral load of 600. His hepatitis B surface antigen was negative, toxoplasma and CMV antibodies were detected, LFTs showed ALT 158 consistent with his hepatitis C....He has had no problems with oral candida recently. I have therefore asked him to stop taking regular fluconazole....He should continue on his current therapy of AZT 250 mg b.d Lamivudine 150 mg b.d Saquinavir 600 mg t.d.s. I have arranged an ultrasound scan of his abdomen in view of his chronic hepatitis C and arranged to see him in 2 months. I have told him that his condition is satisfactory and he may will be candidate for Saquinavir soft gel when his becomes available as absorption is much improved.

14.05.1999 Radiology ultrasound. Liver is of normal size and echogenicity with no focal abnormality seen.....There are one or two small mobile calculi within the gall bladder....

18.05.1999 Letter from I Stephenson (Infectious Disease). He is well with no current problems. His recent investigations show CD4 160, viral load 600 copies, hepatitis B surface antigens negative, ALT 158, WBC 3.3, Hb 13.6. I have requested a hepatitis C PCR, ultrasound abdomen, repeat viral load and CD4 count today...

18.05.1999 Leicestershire Pathology Service. HIV 1 RNA by PCR: Positive.

20.05.1999 Infectious disease unit out patient notes. HBsAg -ve, No Hep C results...Well no current problems. Rpt HCV RNA.....

21.05.1999 Leicestershire Pathology Service. RT-PCR for HCV RNA. Positive by PCR.

## ANONYMOUS

03.08.1999      Infectious disease unit out patient notes. PCR HCV +ve...D/w possibility of HCV Rx/leave be. Need to watch viral load + consider changing HAART.

03.08.1999      Leicestershire Pathology Service. HIV 1 RNA by PCR: Positive

10.08.1999      Letter from I Stephenson. His HIV viral load has risen slightly to 3000 copies and his CD4 count has slightly dropped to 130. He is hepatitis C PCR positive and has an ALT of 201.....Otherwise he is well with no current problems....There is little point in considering treatment for his hepatitis until his HIV is controlled with his CD4 count a little higher.....

05.10.1999      Letter from S Bhaduri (GU Medicine). He is very well and essentially asymptomatic. His ALT has crept up to 201, viral load has risen from 3000 to 4000. In contrast, however, his CD4 has doubled from 130 to 260! The latter may be a spurious result.....I will discuss with Dr Wiselka the merits of organizing a liver biopsy to further address his hepatitis C problem with his CD4 count at present, would he benefit from treatment for hepatitis C.

05.10.1999      Leicestershire Pathology Service. HIV 1 RNA by PCR: Positive

07.12.1999      Infectious disease unit out patient notes. HIV Hep C....considering treating hep C when CD4 increases. Has increased ALT. Hep C RNA +ve. Live USS (N)

07.12.1999      Letter from M Wiselka...He feels well, has no particular problems with his medication although his viral load has been persistently positive at a relatively low level of 3000. His CD4 count declined slightly to 230. His hepatitis C continues to be active with mildly abnormal LFTs and a positive PCR test earlier this year. I discussed the situation....and decided to change his

## ANONYMOUS

treatment to a combination of ddl, D4T and nevirapine. I checked his viral resistance studies today and will see him in one week to assess to new treatment. I have warned him of the possibility of a rash with nevirapine. Once his CD4 count improves and the HIV is under control we might consider further therapy for his hepatitis C. We do not currently perform biopsies on haemophiliac patients...

07.12.1999      Leicestershire Pathology Service. Reverse transcriptase. K70 R mutation – is associated with adefovir resistance. M184 V mutation – M184 I and M184 V are associated with resistance to 3TC and possible resistance to ddl and ddC.

Protease. A71 T mutation. A71V/T is associated with resistance to IDV, RTV, SQV & NFV when present with other mutations. HIV genotype: Type 1, subtype B. These results were telephoned to Dr Wiselka. RT mutations suggest 3TC and early AZT resistance while protease mutations probably indicated nature polymorphism.

14.12.1999      Infectious disease unit out patient notes. Tolerating medication well. Did not understand difficulties with DDI administration ie when to take and in isolation. Fully explained & patient information sheets given. ....

20.12.1999      Infectious disease unit out patient notes. No problems. Still has difficulty taking DDI without interfering with food/drugs etc.

04.01.2000      Infectious disease unit out patient notes. Increased Nevirapine. No problems, no rashes. Forgets DDI occasionally – stressed the need for compliance again! Feels under the weather today – 'flu' like symptoms. Refused bloods. See in clinic in 2/52 bloods then.



## ANONYMOUS

18.01.2000      Leicestershire Pathology Service. HIV 1 RNA by PCR: Positive

18.01.2000      Letter from S Bhaduri. He remains well and is tolerating his medication with little in the way of side effects and has now "adapted" to using ddl in the morning.

29.02.2000      Care transferred to the Royal Free Hospital following move to London.

21.03.2000      Review in Special Combined Clinic (Royal Free). I understand that he has been on treatment for his anti-retroviral therapy since 1998 when his CD4 count was 130 and his viral load was elevated. Initially he was started on AZT, 3TC and Zidovudine....however he became detectable with a viral load of 4,000 copies/ml and his CD4 count again fell....decided to change him on to ddI, D4T and Nevirapine and to continue his Dapsone prophylaxis. He has tolerated this regime well. The only tablet that he has difficulty taking is the ddI.

22.01.2002      Letter from Dr Yee to M Wiselka. Dr Johnson would like to request a resistance assay performed on the stored viral load blood sample, that you have in Leicester, before he started the combination of ddi, nevirapine and stavudine.

28.01.2002      Letter from M Wiselka to Dr Yee. I note your request for a resistance assay performed on the stored viral load blood sample we have in Leicester before Mr **GRO-B** was started on anti retroviral therapy.

07.02.2002      Letter from Public Health Laboratory Service to Dr Yee at the Royal Free Haemophilia Centre. I enclose a copy of the results of the viral resistance profile performed at that time in Dr Deenan Pillay's laboratory in Birmingham. As you can see the

## ANONYMOUS

RT mutations suggest early AZT resistance while protease mutations indicate viral polymorphism.