

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1242001

Exhibits: WITN1242002 - WITN1242005

Dated: February 2019

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 I was born on GRO-B and I live at GRO-B
GRO-B I am married and GRO-B I work in GRO-B
2. I provide this witness statement in response to a request under Rule 9 of the Inquiry Rules 2006.
3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

4. I have severe Haemophilia A with a baseline Factor VIII level of 0.01 iu/ml which was diagnosed GRO-B from a lump on my back that my parents found. My father was questioned on the nature of this lump by the GP and the Police and had to endure accusations of child abuse. On or around GRO-B
GRO-B I was taken to Birmingham Children's Hospital where after some

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tests, my parents' were then sat down and were informed that the lump was as a result of me having Haemophilia A. This condition was then explained to them as neither of them knew about it at the time as no one else in my family was known to have suffered from Haemophilia.

5. The treatment available in the 1980s was a product called Factor VIII and this was administered to me in [GRO-B] in the Haemophilia Unit at the Birmingham Children's Hospital each time I had an internal bleed. My parents were then trained to administer the treatment at home from around [GRO-B]. I was first given Armour Factorate products, then moved onto BPL products around [GRO-B] and then to Alphanate around [GRO-B].
6. I was treated at the Haemophilia Unit at Birmingham Children's Hospital from [GRO-B] by Dr Hill. In or around [GRO-B] when I was [GRO-B] years old, I was transferred to the [GRO-B] under the care of Dr [GRO-B].
7. At some point in 1984, while I was about [GRO-B] years old, I believe that I was given an infected bottle of Factor VIII that was supplied from America. This is confirmed in a letter from Dr Hill to Dr [GRO-B] dated 9 April 1999 which is exhibited at WITN1242002. I also enclose copies of all batches of Factor VIII which I received in 1984, along with my UKHCDO 04 Patient annual treatment record for this period which are exhibited at WITN1242003.
8. I must stress at no point during this time were my parents informed of or even made aware of any risks associated with or linked to the Factor VIII product. They were only told what the treatment was meant to do, however, they were not told of, or offered any alternative treatments, so they did not really have a choice.
9. I was infected with Hepatitis B, non-A non-B Hepatitis (later known as Hepatitis C) and HIV.

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10. From my medical notes I can see that by back-testing stored samples, I first tested positive to HIV on or around 6 April 1984 and there is an undated blood test when I was **GRO-B** showing that I was HTLV-III antibody positive.
11. It was only when I started to suffer from jaundice symptoms, **GRO-B** that I was admitted to hospital on or around 22 January 1985. I believe that my parents were told that I had contracted Hepatitis B, non-A non-B Hepatitis and HIV, by Dr Hill and the head nurse Sister Marian, who both brushed it off at the time as being '*one of those unfortunate things*'. My parents were not told of any risks of coinfections but instead were told '*he's a child; he'll be fine*'.
12. When my parents were told that I had contracted Hepatitis B, the hospital also notified the Education Authority and as a result, **GRO-B**
GRO-B My father went to the press and two articles were printed about the **GRO-B** who had been infected with Hepatitis B at Birmingham Children's Hospital, which are Exhibited along with an article dated **GRO-B** in the **GRO-B** **GRO-B** which was sent to Dr Hill by the Director of Education at WITN1242004. I was excluded from school until around **GRO-B** after I had cleared the Hepatitis B.
13. While I was administering the treatment myself at home, I was still going to the hospital for regular check-ups, however, I was not made aware that I was infected. In or around August and September 1993, **GRO-B** **GRO-B** I attended what I thought was another routine check-up appointment with Dr Hill. I had had many appointments with Dr Hill over the years but this time he was very different. He started the conversation a little different that day, trying to prepare me for what he was about to say.
14. He explained to me that some years ago there had been an unfortunate incident resulting in a number of Haemophiliacs becoming infected with a number of conditions. He named them all and I remember the last one, HIV / AIDS, being the one that was most prominent in my mind. He then explained that I was one of the unlucky patients who had contracted all of the viruses.

15. When I was told about my infections by Dr Hill, he explained that my parents already knew and I was being told because I was older and it was time for me to take control of my own condition. Dr Hill was very professional throughout the appointment but that conversation still haunts me to this day. I can remember the numbness I felt, along with still being able to remember the way that the consultation room was decorated and I can still see the children's drawings pinned to his wall.
16. Growing up with the knowledge of my illnesses had various impacts on my life such as missing many days of school, forming relationships and making difficult lifestyle choices.

Section 3. Other Infections.

17. I am aware that I could have been exposed to vCJD from treatment involving blood products. A letter from Dr Will to Dr **GRO-B** dated 23 January 2001 confirms that I received Replenate 500 IU via size FHE4579. My UKHCDO records show that I was tested for vCJD on 1 October 2004 and 25 August 2007.
18. I do not know if there were other things that I contracted or was put at risk of contracting that I wasn't tested for.

Section 4. Consent.

19. I believe that I went through testing on my blood without my parent's knowledge, consent or being given full and adequate information.
20. When I was older I participated in studies and gave consent for my data to be used in studies. This included identifying my genotype as 1a.

21. I do not believe that I was ever treated without my parent's knowledge or consent but they were never given full information about any potential risks or alternatives so this cannot count as true consent.

22. I was involved in research into the use of high purity product BLP85M as I was HIV seropositive around June 1992 and also into the use of Interferon as a treatment for chronic hepatitis C in children as seen in the attached letters and notes which are Exhibited at WITN1242005.

Section 5. Impact

23. In the mid 1990s when Dr Hill told me of my infections, I thought my life was over. I felt that it shattered all my plans of a normal life such as finding a wife and having children of my own and even growing old. I was almost [GRO-B] years old and I felt that my world was crumbling. All I wanted to know was when I was going to die.

24. It definitely had a big psychological impact on me as I didn't see the point in doing anything and I constantly questioned everything. I hated the thoughts that used to go through my head. My behaviour soon spiralled out of control. I wasn't a nice person to be around and I was always snappy and didn't want to know or be told anything. I was just angry at the world.

25. On and off I did suffer from some form of depression and did act out towards family and friends, all the time knowing in the back of my mind that the illnesses that I was suffering with may one day be too much for my immune system to deal with. At times I felt like there was a ticking clock and I had already been issued my death sentence.

26. I met my wife in [GRO-B] when I was about [GRO-B] years old and about six months later I realised that she could be the one. This was my first proper serious relationship because with all the other girls I just broke things off in case it started getting serious as I did not want to tell people. The thought of eventually having to have 'that' conversation terrified me beyond belief as I was scared to lose her. After about nine months of going out I told her about

my infections and she was so understanding and stood by me. Telling her was the hardest thing that I have ever had to do. She has never judged me but also wants answers from the hospital as to why this happened in the first place. We have now been together for well over **GRO-B** years.

27. The main physical affect from the infection was initially jaundice symptoms aged around **GRO-B**. Then in 2005, when I was about **GRO-B** years old, I contracted **GRO-B** which is a serious infection that often affects people with HIV. I struggled to breathe and stand up and suffered from a horrible cough for about six months. I was even hospitalised for a number of weeks. If I had not gone to the Haemophilia centre about it one consultant told me that I would have died, and when I told them about the illness they seemed to be expecting it.

28. Once the **GRO-B** was under control I was given antibiotics and antiviral therapy drugs to combat and supress the HIV and I am still on these treatments now, called Combivir and Atripla. They used to be two separate tablets but have now been combined into one tablet. I am tested every six months and my HIV is almost undetectable. I was told that I was fortunate to contract HIV when I was young because my immune system can cope now as it has developed with the infection.

29. I have been given four treatments for my Hepatitis C infection. I had my first course of Interferon at Birmingham Children's Hospital when I was around **GRO-B** years old. This lasted for about 24 weeks before I was told that it had not worked. I had a second course of the treatment in around 1996 when I was around **GRO-B** years old which lasted about three months, which again failed. I started a third course of Interferon and Ribavirin at the **GRO-B** **GRO-B** Hospital in **GRO-B** around 2006, which again failed. In 2016 I started a new tablet that became available and this cleared my Hepatitis C in around November 2016.

30. These courses of treatment had major effects on me. I was constantly tired and suffered from flu like symptoms and nausea. I used to hate having the

injections as I knew that they would make me feel sick and unwell. I was doing the injections for the treatment myself, however, I was already used to this as I had been administering the Factor VIII myself since around GRO-B when I was around GRO-B years old.

31. I suffered no real side effects of my HIV treatment. I used to get fatigue and drowsiness but because I used to take the treatment at night, the only real issue was dealing with the children during the night. I am still on this treatment so I have become more used to it now.
32. I have always had to pay more for insurances like travel insurance and always had issues with getting a mortgage so I decided not to declare information about my infections. I have never got life insurance and so my family have never been secured in this regard.
33. Because my HIV infection is almost undetectable, I was told there was a 99% chance that I would not co-infect anyone and so I was able to have kids naturally. However, the thought of knowing that I could pass my infection on to someone else was very scary and I was anxious and constantly paranoid about this, so my wife and I decided to use IVF instead.
34. The MacFarlane Trust only provided one treatment of IVF only for people infected. This one treatment failed and so they said I had to pay for further treatments myself. The GRO-B Hospital wrote to them with me and made my case. After about 9 months I was then awarded funding for another course of IVF, which worked. I paid about £2,500 for the second IVF but this was later reimbursed by the MacFarlane Trust.
35. Socially there was a massive impact on me as I was constantly dodging questions about my infections. I was also living with constant paranoia, as all the 'what if's' were constantly running through my mind.

Stigma

36. Children can be nasty and although I did not tell anyone about my infections, they knew of my Haemophilia. Neither my parents nor I were able to talk to anyone about our situation and with the stigma, having people constantly accusing me of having HIV and telling me I was going to die was very difficult to deal with. I always used to tell people who asked me that I was fortunate and did not get any infections. I was so worried about the stigma.
37. I was forced to live in silence with HIV and Hepatitis which are still always a big cloud over me. Had to pre-plan everything through my life from relationships, to where I was working, to where I was going on holiday. This made me have a really negative outlook on life.
38. Not being able to tell anyone was difficult to deal with and even now, not many people know. My wife is very distraught at the situation and about how I was infected; due to the negligence of the NHS. This whole ordeal has in turn put strain on my wife and her parents, as they all have no one other than who is already in our tight knit circle to confide in. This has left us all very isolated and at times secluded. I am very grateful to all those who know, and who have supported me. I have felt relieved over the past 18 years knowing I can finally talk to some people, although I still feel a strong sense of guilt knowing I have now passed some of my burden over to those that now know. Even though I would very much like to include other family members and even close friends, the stigma of the condition still prevents me doing this. The more people I introduce, the harder it will be for the containment of my personal information. This is now even more prevalent with our children attending school. If my condition was to be public knowledge, I feel my children may be subjected to segregation from other children's parents resulting in difficulties for them to find friends of their own.
39. I still feel stigma even to this day. Even now I lock up all the thoughts of my past in the back of my mind, in order for me to be able to deal with it all a lot better.

40. I suffered with depression from all of this and although I have not had counselling, talking to people at the Haemophilia Unit in the **GRO-B** Hospital has helped me greatly. This is why I think actual counselling would have benefited me. My coping mechanism has been joking and laughing everything off. I used to act out and always used to think *'what is the point, I am going to die soon'*. Eventually, as the stigma died down, I changed my outlook on life and decided to live my life to the most I could. I focussed my aggression and became an adrenaline junkie. I realised the hatred I had for everyone and everything had to change.
41. In **GRO-B** was also diagnosed with a **GRO-B** type of cancer most commonly found with patients who are also suffering with the effects of HIV. This was another devastating blow and I had to endure over 6 months of chemotherapy to try to eradicate it. This treatment however did have a positive outcome, and to date I am still in remission and cancer free. Telling people straight away was a weight off my shoulders. I don't know if this cancer was a result of my infections but I would like to assume it was a separate issue to my conditions and the cancer was totally unrelated.
42. With regard to other treatments, I was also always put in isolation for even simple dental procedures, and my appointments always took time due to extra precautions.
43. My parents suffered a great deal, from back when they were both told of the heart breaking reality that their only child had been given multiple life threatening viruses, caught from a contaminated batch, by the very people they entrusted their son's well being to. They had no information about the viruses and felt their son's future had been taken away. They were forced to suffer in silence as they had no one to turn to with the stigma around and they could only talk to the hospital staff, who were the same people who had contaminated their son.
44. I feel that my education suffered as I regularly missed school due to my infections and my regular hospital visits for injuries such as with my ankles. I

also had occasions where I simply did not want to go into school as I was not feeling up to it. Towards end of my time at school, when I was sitting my GCSE's exams, my mind was elsewhere on my infection and I did not see the point in sitting the exams. After this I took a one year GNVQ course for business before going to work in the retail industry.

45. When I got **GRO-B** around 2005, I was off work for about **GRO-B** and so I had to give up my job, which naturally had financial implications.

46. Other financial implications due to my infections were the struggle of obtaining insurances and paying much higher premiums, paying outright for IVF treatment (although I was reimbursed) and not being able to get certain jobs.

Section 6. Treatment/Care/Support

47. My only issue with receiving any treatment was for the new tablet to clear the Hepatitis C in 2016. In or around 2014 I was told that a new treatment had just become available with a high success rate of eradicating the Hepatitis virus all together. The news was well received by my now wife and I, however, we were both devastated to then find out that I did not fit the current eligibility criteria to receive this treatment. Only patients who showed chronic liver damage were considered and in 2015 that my Fibro scan did not show that my liver was bad enough to get funding for this new tablet.

48. I pleaded with my Consultant who was sympathetic but who was bound by NHS guidelines. I even wrote to my MP's **GRO-B** and **GRO-B** to try and get them involved. Eventually the guidelines were slightly changed and the criteria to receive this tablet were lowered. I was allowed the tablet after two years when funding for it became available. I am now in remission stage of liver cirrhosis and I am tested once a year. I feel that the new drug for Hepatitis C should have been made available to me earlier.

49. Counselling was never offered to me. I feel that it should have been offered to me as I believe that it definitely would have helped me and probably would have stopped me feeling so down and acting out.

Section 7. Financial Assistance

50. My parents found out that funding was available and in around 1991 we received a litigation lump sum but they had to sign a disclaimer otherwise we were told we would not get the money from the MacFarlane Trust. Then they set up a monthly payment scheme, and in recent times I receive about £1,200 a month. I was allowed to apply for different type of grants. However, they made us beg and fight for money from these grants.
51. In or around [GRO-B] I was introduced to a man at the [GRO-B] Haemophilia Centre called [GRO-B] who then applied for everything on my behalf. Whenever any form of compensation became available to me he would explain to me what I was applying for and help me complete the forms. Difficulties of applying for these compensations were minimised thanks to [GRO-B] and the Centre, but they were still time consuming and difficult and would have been so much harder without [GRO-B]. I believe that these trusts could have been managed a lot better and looking back on it the process could have been made such simpler. I also understand that they were paying bonuses to their staff and feel this money should have been coming to us. I only realised this later and originally I thought it was very good.
52. The MacFarlane Trust also provided funding for our IVF Treatment. For this first lot of funding I still had to write to them, helped by the hospital, as the MacFarlane Trust said my HIV was undetectable. The second payment for IVF was a lot harder; I had to submit receipts and was told they might only pay half of my expenses. Eventually, after the [GRO-B] Haemophilia Centre wrote to MacFarlane they agreed to reimburse me in full for my second IVF reimbursement but this took about six to nine months. As much as I appreciated their change of heart, I still felt as though my wife and I should

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never have been in the position of what at the time seemed to be begging for help.

53. I also applied to the Skipton Fund and I received a stage one payment of £10,000 for my Hepatitis C.

54. Through EIBISS I have another two separate payments coming in. They are £1500 a month and £1900 a month.

Section 8. Other Issues

55. I have no grudges against the medical staff who I feel, were acting within their means; unless of course they knew more than they let on.

56. It seems to me as though whoever authorised the acceptance of the blood from America that had high contamination issues did not care about the risks as the blood was cheap. The attitude seemed to be that *'anyone infected will die soon anyway so do not worry about them; it will only be a small number of people anyway'*.

57. I believe that in the early 1980s the UK was selling its own high quality treatment of Factor VIII abroad and then importing the cheap treatment for us UK patients. They did not care about us.

58. I can accept that mistakes happen and I can even accept it if there were not tests for screening the blood available at the time and they genuinely did not know the risks of using the blood. However, if people knew about the risks of the treatment when I was infected, then I can not accept that. I believe that they took a financial, researched decision and so justice needs to be done. If I infected someone knowingly with HIV then I would go to prison. I believe that the same sentence should be applied if they knowingly infected all of us. The organisations need to be held accountable and pay compensation so our families can be secure. I want financial stability for my family.

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59. My parents should have been told of the risks to me taking Factor VIII, allowing them to make a truly independent and informed decision.

60. I believe that the Public Inquiry should also consider the years over which investigations were blocked and issues were hidden and the way some people have had 'alcoholics' written on their death certificates. We were forced to beg and fight for treatment and then initial compensation, while this scandal was being attempted to be covered up at every opportunity.

Anonymity, disclosure and redaction

61. I wish to apply for anonymity.

62. I am happy to provide oral evidence if it can be in private and be anonymous.

Statement of Truth

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

Signed

GRO-B

Dated

26/2/2019.

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Medical Chronology

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

29/5/1981 [GRO-B]

4/6/1981 Haemophilia card issued and Oxford notified

1981 received Factorate at Birmingham Children's Hospital

26/7/1983 last negative HIV test

1984 given 3 batches of Armour FVIII (Factorate) X616111, X603111, X41906 from UKHCDO records

6/4/1984 date first positive HIV test. Back testing of stored samples showed that [redacted] was HIV seropositive on a sample from 1984 (letter Dr Hill to Dr [GRO-B] 9/4/1999)

Undated blood test age [GRO-B] HTLV-III antibody positive

22/1/1985 Outpatient Continuation Sheet Haematology Service - Jaundiced. Notified to be yellow this am. Urine dark for 2 days. Stools pale for 2 days. Not eating for 4 days. Vomiting 2 days ago not vomited since. Anorexic. Confirmed Hepatitis B Antigen Positive 1:8000. Treatment given 0 S/B [GRO-B] Parents to EBH for Immunoglobulin. Comment - Home. See SOS.
Blood test - Positive for hepatitis B surface antigen (HBsAG) to a titre of > 1:8000 by passive haemagglutination

7/2/1985 letter [GRO-B] Senior Registrar in Haematology to [GRO-B] (GP) 'this patient has recently been found to be hepatitis B surface antigen positive. His parents are aware of this and I have written to the School Medical Officer with this information.'

18/2/1985 letter Dr Hill to parents 'As you are aware, your son has recently contracted hepatitis B and is now a carrier of the hepatitis B virus. There is a risk that this infection could be transmitted to other family members under a limited number of circumstances. All the other children in the family, as well as yourselves, should be tested and if negative for hepatitis B, then it is advisable that you are given the hepatitis B vaccine that is now available.'

16/3/1985 Clinical notes - Notification of infectious disease (infective Hepatitis) sent to [GRO-B]
[GRO-B] (date of onset 22/1/1985)

19/3/1985 letter Dr Hill to [GRO-B] 'I was recently at [GRO-B] [GRO-B] to discuss the present eight cases of Hepatitis B that we have

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- had following the use of commercial Factor VIII concentrates, with **GRO-B**
GRO-B One of the boys ... appears to be clear in the antigen and so we hope that the other boys ... might eventually clear the antigen. Obviously this would make the situation with **GRO-B** schooling when he starts later this year much simpler. I understand that **GRO-B** has **GRO-B** and would be grateful if you could confirm if you are looking into this matter.'
- 24/6/1985 Father pursuing **GRO-B** exclusion from school in the press – almost daily telephone enquiries from the press. Current Virology – Surface B antigen 1 in 2. Negative for surface antibody. Positive for cure antibody.
- Sept 1985 **GRO-B** due to concern about hepatitis B
- 13/9/1985 letter from **GRO-B** to Dr Hill attaching report in **GRO-B** suggesting a causal relationship between Hepatitis B and AIDS
- 4/12/1985 Dr Hill had meeting at school to discuss his return
- 12/12/1985 letter Dr Hill to **GRO-B** advising **GRO-B** cleared hepatitis B and recommended schools should use rubber gloves when treating with haemophiliac boys of when dealing with blood spillage from them and non-haemophiliac children.
- 20/12/1985 letter Director of Education to Dr Hill 'I am now quite satisfied that it is safe to allow **GRO-B**
- Feb 1986 hepatitis B surface antigen negative - cleared the virus
- 1986 began regular home treatment (after cleared hepatitis B)
- 18/4/1986 letter **GRO-B** (dental children's hospital) to **GRO-B** Consultant Haematologist 'Furthermore, as he has HTLV3 positive, the risk of creating aerosols particles is high. This will mean that precautions will have to be taken to clean the Out-patient surgery.'
- 21/7/1986 letter Dr Hill to **GRO-B** (GP) 'The current state of our knowledge is that 10% of haemophiliacs exposed to this virus (HTLV-III) will go on to develop problems, but some people feel that the proportion may be higher than this eventually. The parents are aware that **GRO-B** has been exposed to HTLV-III and at the moment he is well, but they are aware of the possibility of long term sequelae.'
- 13/2/1987 HIV positive
- 13/11/1987 Clinical Note HIV +ve, Immune Hep B
- 10/8/1989 letter Dr Hill to **GRO-B** (GP) detailing meeting with parents 9/4/1989 to discuss risk of HIV

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- 29/3/1991 Dental Dept. notes HIV +ve, hep B +ve
- 5/6/1992 parents signed consent to change to BLP 8SM Factor VIII product
- 11/6/1992 memo from Dr Hill RE: Implementation of the recommendations on choice of therapeutic products for the treatment of patients with Haemophilia A, Haemophilia B and Von Willebrand's Disease
- 12/6/1992 letter Dr Hill to **GRO-B** (GP) 'I saw the parents of this boy on 5.6.1992. The purpose of the visit was to discuss the recommendations of the Regional Haemophilia Centre Directors Committee. They have recommended that all patients who are HIV seropositive should be treated on one of the purer Factor VIII products. The reason for these recommendations is that although there are a number of inconclusive studies, there is one study that has shown that those patients who were HIV seropositive and treated on a purer Factor VIII had stable CD4's while other patients had unstable CD4 counts. Clearly the Centre Directors are anxious that if there is going to be a benefit that this should be relayed immediately to patients and so we are implementing the change. This does have implications in terms of increased costs and this is currently being looked into in order to try and obtain the further finance. The reasons for this and any potential downside complications like the reported in ceased incidence of inhibitors in newly treated patients put on purer Factor VIII has been discussed with the parents. There are two purer Factor VIII's currently available and they have chosen for their son to go on to BPL 8SM and have indicated they do not want him treated on Armour Monoclate.
- 13/8/1993 Clinical note – brought for counselling re HIV – not told previously of HIV seropositivity. Both parents present. Told how HIV infection happened & how HIV virus affects lymphocyte cells. Told that some patients can become ill & that why we do best to make sure that he is staying well, which is the case at the moment. Told he can't give it to anyone except by sex or if given his blood. Need to not tell people at this stage. Clearly shocked and Parent's very support & good
- 17/8/1993 letter Dr Hill to **GRO-B** (GP) detailing meeting with **GRO-B** and parents to discuss HIV infection
- 3/9/1983 letter Dr Hill to **GRO-B** (GP) detailing meeting with **GRO-B** alone to discuss HIV infection
- 18/5/1994 letter Dr Hill to **GRO-B** (GP) 'I have spoken to **GRO-B** and **GRO-B** about the recent result we have obtained showing that **GRO-B** has hepatitis C. As you are aware tests for hepatitis C, which previously was called non-A non-B hepatitis, have recently become available. This result in **GRO-B** is not unexpected as we expect most haemophiliacs who receive concentrates in the early and middle 80's to have been exposed to this virus, but fortunately newer concentrates that have

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been virucidally inactivated have ceased to transmit this infection to haemophiliacs. At the moment [GRO-B] liver function tests are within normal limits and, therefore, there does not appear to be any effect from the hepatitis C. It is not clear at this point in time what the natural history and we will be liaising with [GRO-B] the Consultant Hepatologist, in order to set up joint clinics to follow these boys.'

June 1994 shingles

6/2/1995 Genotype 1a Hepatitis C

14/3/1995 Hepatitis A vaccine

23/9/1994 Hepatitis A vaccine

27/3/1995 letter Dr Hill to [GRO-B] GP) 'With regard to the hepatitis C, I have explained to [GRO-B] that we are currently having discussions with our hepatology colleagues and are waiting to know whether or not the regional contract for haemophilia will contact funding for treating hepatitis C. There is clearly a need to undertake treatment for the haemophilia population that has been infected with hepatitis C, as there is evidence that the sooner treatment with Interferon is given after infection, then the more likelihood there is of getting a satisfactory response to treatment with Interferon. Clearly if the regional contract does not find funding for this, then we will need to have discussions about how we ensure that essential treatment is provided for this young man.'

21/9/1995 letter Dr Hill to [GRO-B] Consultant Hepatologist 'I would be grateful if you could see this young man who has severe haemophilia A. He was treated in the past with non-virucidally treated products and when HIV testing was introduced, we found he was already HIV seropositive. The earliest sample that has been found to be HIV seropositive by back testing was in 1984. In 1985 we have documented that he was hepatitis B surface antigen positive, having presumably become infected with hepatitis B from his treatment. He then went on to develop hepatitis B core antibody and to become immune and became hepatitis B surface antigen negative by February 1986. Clearly when HCV testing was introduced, we were not surprised to find that [GRO-B] was hepatitis C seropositive and testing in Edinburgh has shown that he is also HCV PCR positive and that he genotype of the HCV is 1a. Subsequent quantitative PCR showed an HCV titre of 4×10^6 HCV RNA per ml. As far as his HIV is concerned, he remains asymptomatic and still has a normal CD4 count.'

7/11/1995 Clinical note - [GRO-B] year old. HIV positive (... CD4), Hep B (cleared), Hep C

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23/2/1996 Clinical note – sexually counselled re HIV. Any partner must be counselled & informed before sex. Can have girlfriends. Can get married but HIV & safety of partner and children a big issue

1/7/1996 consent form signed by mother for randomised study of two treatment regimes of interferon alfa-2a for chronic hepatitis C in children with haemophilia. Interferon commenced

22/11/1996 tolerating Interferon extremely well ... the only difficulty is that his weight has slipped slightly from 75th to 25th centile which we often see at this stage: GRO-B

7/1/1997 will stop Interferon as no response

27/4/1998 changed treatment to Alphanate

29/4/1998 letter Dr Hill to GP. 'Because of the perceived risk of new variant CJD with British Factor concentrates, I have discussed with GRO-B and his father about changing to a Factor concentrate which is made from American donor plasma. They understand this product is made from plasma of donors that are HIV, hepatitis C and hepatitis B serologically negative and that the product is treated by a variety of virucidal methods. Because BSE is not a problem in the States, it is unlikely that donors there will have new variant CJD. They have decided they wish to switch to the American Factor VIII concentrate, Alphanate, and this will be implemented as soon as possible.

3/11/1998 implicated batches of Alphanate for product recall including A58725A & A58715A given to GRO-B

16/11/1998 recall – implicated batches of Alphanate available for use – he is happy for GRO-B to continue on this product while we have supplies of Alphanate even though it is likely he will switch to Fendi (unlicensed product from Gifols) when he transfer to the GRO-B Hospital. GRO-B will return existing batches today and take the new Alphanate batch – Mr Hill

9/4/1999 letter Dr Hill to Dr GRO-B with summary of medical history

20/5/1999 care transferred to Dr GRO-B, GRO-B

1/10/2004 assessed for vCJD by GRO-B – at risk

2006 Interferon treatment - failed

28/8/2007 assessed for vCJD Prof F G H ? – at risk

Nov 2016 successful treatment for Hepatitis C