Witness Name: GRO-B
Statement No: WITN3118001
Exhibits: WITN3118002 - WITN3118006
Dated: August 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 1947 and I live at GRO-B GRO-B. I married GRO-B on the GRO-B and we are both retired. We do not have any children.

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006. I am aware that my husband GRO-B will also be providing a statement (Witness Number GRO-B).

3. This witness statement has been prepared without the benefit of access to all my 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

4. I was born with type 2B Von Willebrands disease but it took a long time for me to be diagnosed. As a child I bruised a lot and at one point I was an inpatient for about 3 months. I have a brother and sisters but no one else in my family has been diagnosed with Von Willebrands. My mother did have a child before me who sadly passed away from hemorrhaging so it possible this baby had a bleeding disorder. In August 1998 my consultant Haematologist categorised me as a '*moderately affected patient*'. In 1973, my Factor VIII (FVIII) level was 47%, in 1975 it was 45% and in 1985 it was 47%.

5. I was treated at Manchester Royal Infirmary Haematology Department from around 7 years old until we moved to GRO-B, North Yorkshire in 1973 where I was under the care of the Haemophilia Unit of Harrogate Hospital and at the same time under the care of the Haemophilia Unit of St James University Hospital Leeds, which I still attend. I was under the care of Dr L. M. Swinburne at Leeds St James and Dr GRO-D at Harrogate Hospital. Later I was under the care of Dr GRO-D at Leeds and since 2011 Dr L. H. Horn at Leeds.

6. Before cryoprecipitate (cryo) was introduced I was treated with snake venom. My earliest medical records of receiving blood clotting products refer to cryo being given to me at the St James Hospital Leeds Haemophilia Unit in December 1974 when three teeth were extracted. We were told cryo was a miracle and would stop my bleeding. I also had cryo for a bleed from the throat in May 1979.

7. In total I believe I received FVIII on at least 6 occasions. I was first given Factor VIII concentrate (FVIII) on 6 October 1981 by Dr GRO-D during a radical cauterization of cervix as seen in the letters from David Taylor, Gynecologist dated 2 and 13 October 1981, referred to in the medical summary at the end of this statement. I was then given 1,000 units of FVIII concentrated HCB 2952 on the 21 September 1982, as I was coughing up blood as the hospital believed I was hemorrhaging. I exhibit my UKHCDO

patient annual treatment record, patient b2 look up record, patient c lookup confirming I suffered from jaundice on 10 November 1982, an undated letter to me from the Harrogate Hospital Transfusion Practitioner with medical records provided by Harrogate Hospital sent to me around the time of the 2003 litigation and also a more recent letter from the Harrogate Hospital Transfusion Practitioner dated 9 July 2019 which gives details of batches at Exhibit WITN3118002. I note the last document of this exhibit indicates that I was given cryo on 5 and 6 October 1981 which is inconsistent with David Taylor's letters which state I was given FVIII.

8. I was never initially warned of any risk associated with blood products. However, I believe the medical professionals were aware of the risk as I have a letter, shown at exhibit WITN3118003, dated 1 May 1979 from Dr GRO-D, the Harrogate General Hospital Haematology Consultant, to my GP Dr GRO-B which states '*I feel that it would be worth swapping her over to Tranexamic Acid (Cycikkapron) 500 mgs tds for a trial period of 4 weeks. This is an alternative drug for the stabilization of formed blood clots and if it works it will avoid the necessity of repeated injections of cryoprecipitate with the slight risk of Hepatitis or plasma reaction'*. This suggests to me that by 1979 the danger of infection from blood products was understood and I should have been warned.

9. From about 1985 onwards I was aware of the potential danger of infection with AIDS from blood clotting products and therefore I avoided them wherever possible. In the late 1980s, we were occasionally told by St James Hospital doctors, not in the Haemophilia Unit, that we should avoid having FVIII whenever possible because its safety could not be guaranteed and it could lead to infection.

10. I was infected with Hepatitis C (HCV) as a result of being given contaminated blood products for a bleed from the throat on 21 September 1982 (aged 35) and exhibit the Harrogate District Hospital Notes at WITN3118004. Prior to this, as at 8 April 1982, I showed no evidence of hepatitis and my liver function tests were normal.

11. Seven weeks later I was extremely ill with Hepatitis, Bronchitis, Pneumonia, Pleurisy and I was jaundiced. I was given the antibiotic Septrin. The doctor felt where my liver was and said it was swollen. I don't remember the doctor saying I had non A non B Hepatitis when he came to see me, he just said I had '*Hepatitis*'. I thought you got Hepatitis from shell fish or on holiday. Immediately after my infection my laboratory test specimens were stamped HIGH RISK and recorded Non A / Hepatitis as seen at exhibit WITN3118005.

12. I was not provided with any feedback after my infection in September 1982 from the Harrogate Haematologist or my GP to tell me that I had received a new infectious Hepatitis disease, which might have derived from blood products that I had previously been given. My husband was not advised to take any precautions to avoid becoming infected through either sexual intercourse or close proximity. I was not told in 1982 to avoid alcohol or fatty food. From 1982 to 1990 I had an occasional glass of wine, as nobody had told me it was a problem.

13. I was finally informed of my HCV infected status a week before a lobectomy operation on 17 June 1991. The week before the operation I went to see Dr GRO-D to discuss what would happen during the operation. He said I would have FVIII twice a day for 4 days and then every day for 2 weeks. Then he said '*I'm sorry to tell you this but we have found you have HCV'.* The surgeon, Dr Saunders, said he had not operated on anyone with haemophilia, and I had not had a big operation before so there was a 50/50 chance of survival. As I had been told I had a 50% of passing away I was more concerned about my operation than the virus.

14. The only advice I remember receiving was that HCV was a virus but they did not know much about it. In 1991 I was finally given information about avoiding alcohol and fatty foods. My husband was then tested and was negative.

15. My medical records include a letter dated 28 March 1995 from Dr GRO-D to my GP which states that '*I did bring up the matter of Hepatitis C infection and*

GRO-B *knows that she has been exposed to this virus in the past. The cause of this would have been the coagulation products she has received and virtually all my patients, who have repeatedly received blood products over the last 20 years are now Hepatitis C positive*'. Dr GRO-D followed up this letter on 4 July 1995 confirming that I was Hepatitis C antibody positive and hepatitis C RNA positive and my liver function tests were abnormal. Both these letters are exhibited at WITN3118006.

16. We were told that HCV was identified in 1989 and I would have expected haemophilia patients like myself to have been tested for it during the next six monthly review. I should have then been given the results immediately, rather than waiting until 1991 to confirm that I had this deadly disease. I therefore believe that the NHS concealed from me the fact that I had the new disease HCV from 1989 until 17 June 1991.

Section 3. Other Infections

17. I was also informed by the NHS in 2004 that I personally could be at risk of contracting Variant CJD (vCJD) from an infected blood product that has been identified as having been made using blood taken from someone infected with vCJD. My understanding is that vCJD can lead to serious illness and death. Although I have not been identified as having vCJD that risk still remains with me. It is yet another threat hanging over me and a source of worry.

Section 4. Consent

18. After I reviewed my Harrogate District Hospital notes I discovered that in May 1985 I was tested for HIV, as seen in the previous exhibit WITN3118004. This ties in with my UKHCDO Patient HIV data show a sample dated 15 May 1985 was found to be negative. Dr GRO-D wrote to my GP on 3 June 1985 to advise I had been tested for HTLV-III (AIDS virus) and was negative but I was not told about this test.

19. We were treated like guinea pigs. I feel like they were testing products on us to see what happened. It is awful to say. Maybe a health minister at the time knew and ignored it. Maybe they thought we would all pass away.

20. The medical note previously exhibited at WITN3118004 dated 13 November 1982 states '*reported to Oxford (22/11/82)*' suggests to me that some sort of national monitoring of non A non B Hepatitis was being carried out in 1982.

Section 5. Impact of the Infection

21. When I first became ill with Hepatitis (when I did not know it was HCV) I was extremely ill. I woke up and my skin was yellow. I got in contact with the doctor and he came to visit me at my home. I could not stop being sick or keep any food down. I went down to nearly 7 stone. The doctor said having a bowl of corn flakes with a lot of sugar would help. Despite living only a 15 minute drive from Harrogate Hospital I was treated at home and received visits from Dr **GRO-D**, physiotherapy and X-Rays at home. This treatment at home seemed extremely unusual at the time but I was told it was because there was a strike at the hospital.

22. As I was so severely ill in 1982 **GRO-B** felt it was appropriate to get in contact with his parents. They came from **GRO-B** and looked after me for a month. I could not have coped without them. They never left my side. Pneumonia, Hepatitis and Pleurisy could have killed me but the extensive physiotherapy that I received removed large amounts of infection from my chest and may have saved my life. It took me about a year to recover from the initial effects of the 1982 infection.

23. For 33 years, the HCV caused me to be constantly tired, lacking in energy, fatigued, tired but unable to sleep properly, being sick, having abdominal pains, being angry, depressed. I had low motivation and low self esteem. During the 33 years that I was infected with HCV I lived in fear of death. I often dreamed about dying. I was fearful all the time that my liver would

suddenly deteriorate because liver cancer and liver failure frequently develops very suddenly with limited advance warning signs.

24. Since being infected with HCV in 1982 my chest has deteriorated and I have bronchiectasis which requires me to take antibiotics and a nebulizer twice a day. I have had many serious chest infections since 1982 which could last for 7 to 8 weeks which I believe may have been caused by the HCV, Pneumonia, Bronchitis and Pleurisy infections I contracted in 1982. I still suffer from nose bleeds, low platelets, bronchiectasis with occasional bleeding from the lungs coming into the throat, asthma, high cholesterol, low thyroxin level, occasional reflux from hiatus hernia, occasional knee problems, arthritis in right hand and low vitamin D level. I think having HCV and liver damage may have contributed to some of these health issues.

25. There were times when we went out with friends and I would have to leave. On one occasion we went to a concert and we had to leave half way through because I felt ill and was extremely tired. It is as if someone sucks the energy completely out of you. You just want to lie down until you feel better. I lacked energy on holidays and could not enjoy them as I used to. This put tremendous pressure and strain on my husband who had to constantly reassure me and comfort me and look after me when I was ill. He would take leave or come home from work early if I was ill, be ready to drive me to hospital at any time if I was ill, do the housework I could not do and he was advised in 1991 not to have sex with me without using a condom to prevent him being infected (until I was cured in 2016). It has been very difficult for both me and my husband.

26. I have coped all my life, there were a lot of times when I could have gone to doctors, but I have not bothered. What could they say? I was better looking after myself at home.

27. In the years which followed my HCV, whenever possible, following the growing understanding surrounding the dangers of infection I avoided blood clotting products. I feared I would be infected with AIDS or more heavily

infected with Hepatitis. However, I was very afraid up and until safe blood clotting products were available that I might have no option other than to risk taking a blood clotting product if I needed a big operation. Due to my fear I made a conscious effort to let myself bleed. I used to lay on the bed with a bowl and just bleed. It used to drain out of my mouth. There were lumps of clots coming out of my mouth. As a result I only used to get 2 or 3 hours of sleep at night. There was also a possibility I could have choked to death. My life was like this for about a year.

28. My fear was so great because people I had met in the clinic would just disappear. I was not going to be one of them. My focus after a while was to survive, I had to put things in little boxes and shut them away. I just focused on keeping myself as fit and healthy as possible.

29. I had always believed that the doctors knew best and I never thought to ask questions. After I was told I had Hepatitis I lost a lot of confidence and questioned everything. The doctors kept a lot of secrets and did not warn me of any risks. If anyone said in the early days *'you have a choice, you can have the treatment to stop the bleeding but we are getting it from America and there is a problem with it'* I would not have chosen to have the treatment. I was not offered a choice though.

30. The HCV caused my liver to become damaged. The liver is involved in preventing infections, so I will therefore have been more likely to catch illnesses. I have now developed bronchiectasis. I followed all the medical advice that I was eventually given, including trying to maintain bodily fitness, trying to avoid any infections from other people, keeping my house warm and not drinking alcohol. This and luck aided my survival.

31. I used to get information from the Haemophilia Society which mentioned that I should be seeing a liver specialist. I had to specifically ask Dr **GRO-D** if I could see a liver specialist. He did not like the fact that I asked and it put his back up for years but he did refer me to Dr Millson.

32. Dr Millson who was a liver specialist at St James liver department has been brilliant with me. In 2009, he was very upfront about the existing treatment and said the side effects were not brilliant but it was worth having a go. In the mean time I was haemorrhaging from the throat and had a chest infection. I was frightened that my platelets would go dangerously low if I added the stress of the treatment to my body. I said to Dr Millson that because of this I did not want to undergo the treatment.

33. I had a fibroscan test of my liver in 2011 and Dr Millson said I was doing well. Treatment was not mentioned to me again until 2012 when Interferon and Ribavirin became available. I did not want to undertake this treatment either because I spoke to other people who had undertaken the treatment and I was advised to hold out for a new treatment that would become available in 2 years if I was well enough. I heard horror stories about people's teeth and hair falling out, high pain levels and other really bad symptoms while they were on the Interferon and Ribivirin treatment.

34. A couple of years later the Sofusbuvir and Ribivirin treatment came in, but at this point I had a new doctor, Dr GRO-D, as Dr Millson was now working in York. Dr GRO-D said they were only going to give the new treatment to people who were seriously ill but the old treatment was still available to me. Following a reorganisation I was transferred to Dr Millson's team in York. Dr Millson offered me the new treatment despite what Dr GRO-D said about it not being available to me. If I was still at Leeds Hospital under the care of Dr GRO-D I don't think I would have received the treatment. I was lucky I had the treatment when I did.

35. I then received the treatment of Sofusbuvir and Ribavirin between March 2016 and June 2016 which consisted of 8 tablets day. It was 3½ months out of my life which I will never get back. It reduced by platelet levels but luckily GRO-B was retired by then so he could take me to Harrogate 3 times a week for blood tests. The tablets made me feel very tired, listless, headachy, dizzy spells and sickly. These symptoms continued for another 4 months after my treatment ended. I cleared the HCV in 2016 aged 69. I was tested in June

2017 and I did not have HCV. I was also tested in July 2018 and I was still clear.

36. Since I have cleared the HCV I can do a lot more physical actives and now play table tennis. However, the infection is still affecting my day to day life. Every morning I have 7 exercises to do on my knees. By the time I finish everything it is about 11.30am. I have to take all my tablets too. The tablets are for low thyroxin, low vitamin D and high cholesterol. The antibiotics I take to prevent bronchiectasis infections are taken an hour before food or two hours after. Then I go on my nebuliser machine which wards off bronchiectasis.

37. I had a problem with a local dentist who said *'I'm sorry, but I can't treat you'*. He said it was because I had HCV. I am now at another dentist who is very good because he treats people with haemophilia.

38. I lived in great fear that if people found out I had HCV I could loose either my job or my friends because people would be frightened of being infected by me. It made me feel depressed, worthless, tainted, inadequate and that I was a damaged person who put other people at risk of infection. I also felt anxious and tense because I had to be constantly on my guard to prevent people finding out. Some people, including friends and acquaintances who found out about the HCV decided not to mix with me socially, which was really unpleasant and made me feel that I had been rejected. They were nice and sympathetic but then they would not invite us out again because they were worried if they touched me or if I bled they could get infected. People did not know how easy it might be to contract Hepatitis C and therefore avoided me.

39. I kept HCV very close to my chest as a result. Some people also associated HCV with AIDS. They also didn't understand haemophilia so if I said I had HCV from a blood product they would not understand. I told certain friends as I feel better when I speak to people. Since I have been cleared I have told more people.

40. The HCV blighted my working life and I tended to work part time due to my general fatigue and other side effects. I felt more tired, less well, less energetic, physically weaker and had lower concentration levels than before the infection. This prevented me from working longer hours, studying to improve my skills and getting better paid and more enjoyable jobs. My last job was as a lab technician in a school where I worked Monday's. However, I retired aged 51 as I was getting increasingly tired and wanted to put all my efforts into staying well and keeping fit. I have therefore lost out considerably financially due to the debilitating physical and mental side affects caused by HCV.

41. In 1991 I was advised by Dr GRO-D to not have too many fatty foods as they tend to affect the liver. I took this seriously and to this day I still avoid fat. I eat a lot of gluten and lactose free products. It has been very expensive to sustain this diet as I am buying more expensive products. Luckily GRO-B was on a good salary. I also get cold very quickly so I have the heating on a lot. I feel the cold so I have the fire on most of the time so this is also expensive.

Section 6. Treatment/care/support

42. I was not provided with adequate care or support. As mentioned above I am not sure whether I would have been offered Sofubivir and Ribavirin so early if I had not been transferred to Dr Millson's team. I believe I should have been offered the new HCV clearing treatment straight away. The people who sign the treatment off were saying '*you have to be dying before you can have it*'. The government did not give the medication to people right away even though they had damaged our health and we had been waiting a long time for treatment. They were hypocrites. They were allocating treatment like a lottery. People have died because they were waiting for the treatment and I find it really upsetting. I was in the right place at the right time. Other people have not been as lucky and that annoys me.

43. Neither counselling nor psychological support has ever been offered to me.

Section 7. Financial Assistance

44. My mum rang me and informed me that she had seen on television that the Government were giving compensation for HCV and HIV. GRO-B then rung the Haemophilia Society and they said it was true. We were then given the number for the Skipton Fund and they sent us a form. Dr GRO-D and Dr Millson had to sign this form.

45. We received a payment of £20,000 in 2004 from the Skipton Fund but we had to sign a disclaimer saying we would not sue them.

46. Since 2015/2016 I have received the winter fuel payment from the Caxton Foundation. When we applied in 2014/2015 they said we had missed the deadline by a couple of weeks and it would not be backdated for the 3 years to 2012/2013 from when I would have been eligible. We therefore had to apply the next year. I was only advised that the winter fuel payment was not means tested by speaking with another infected person. When I had previously looked into it, the impression given to me was that if our household earnt over a certain income you could not claim for it. I found the details about these payments obscure and confusing. I believe this was deliberate to avoid making payments. No one wrote to us to say we were entitled to Winter Fuel Payments.

47. We were also told about other payments but they were going to be means tested GRO-B's salary and pension meant we were above the threshold.

48. In December 2016, we started receiving EIBSS payments and these have been increased since April 2019 to £18,989 per year including the Winter Fuel Allowance.

49. The EIBSS payments information has been communicated properly and payments were back dated to April 2016.

Section 8. Other Issues

50. In about 2003 or 2004 we were involved with an American law firm, Lieff Cabraser Heiman and Bernstein in a legal class action against pharmaceutical companies supplying American blood products. However Lieff Cabraser Heiman and Bernstein wrote to us on 8 December 2004 stating that because St James Hospital, Leeds and Harrogate Hospital had refused to supply details of the brands and batch numbers of blood products given to me in 1970's, 1980's and 1990's, I could not show that I had used American blood factor. Therefore, they could no longer act as our attorneys and could not prosecute any claim on our behalf. Consequently we were not involved in the litigation from December 2004 and did not receive any compensation.

51. I have been in the NHS system since birth and I had a lot of trust in the NHS. That trust has now been broken. I am now 72 years old and I hope to live to see the conclusion of this Inquiry. I believe that someone in the NHS or Government decided that I and over 4,000 other patients with bleeding disorders were just not worth spending money on or bothering about and that is an absolute disgrace. I feel that over 4,000 people with bleeding disease have been treated with utter contempt by past Governments and by the people who in the past designed and implemented the nations NHS strategies to address bleeding disorders. They did not think through what they were doing. They did not adequately research the information that warned of the dangers of what they were doing and when it was clear they should quickly change course they did far too little, far too late and that caused a great deal of unnecessary suffering and cost a lot of patients their lives.

52. Leeds NHS Trust was very unhelpful, very slow and obstructive when I requested a copy of my Leeds medical records for my Inquiry statement. The Medical Records staff said that I had no legal right to obtain a copy of my records although they said they would provide them. Fortunately, my GP and

Harrogate Hospital sent me their copy of some of the Leeds correspondence. However, there is a gap in my Leeds medical records between 1982 when I was infected with non A non B hepatitis and 1989. Leeds has sent me no records showing any review or discussion of my non A non B hepatitis between 1982 and 1989 at their major Haematology unit. I applied for my Leeds medical records on 13 February 2019 and received them in dribs and drabs. The last records arrived on 14 June 2019, four months later. The first set of medical records Leeds sent were from 2000 onwards and there was a statement that records from 1972 to 2000 were in '*overspill*' and implying that they were unavailable. I received an email in March that stated that they had only found 3 pages of records between 1972 and 1996. I then asked for all the overspill records and eventually received records from 1972 to 1982 and from 1989 to 2000.

53. The granting of permission by consultants to release my records seemed to greatly slow the process down and I was left with the impression by what was said that a vetting process was being applied to the release of my records.

Anonymity, disclosure and redaction

54. I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry.

55. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-B ....

Dated....26/08/2019...........

MEDICAL SUMMARY

1/2/1955	severe epistaxis and melena. Treated with Adrenoxyl
9/12/1974	cryoprecipitate 4 units
10/12/1974	3 teeth extracted. Cryo 4 units. 3 units FFP given
13/11/1975	letter from Dr Swinburne to Mr D Dyson, Dental Surgeon St James – she had some dental extractions here in 1974 and bled copiously in spite of the usual Cryoprecipitate cover. In view of this, any further work should be done here as an inpatient
13/11/1975	letter Dr Swinburne to patient – We have now completed the blood tests for which you came to see us recently confirming the diagnosis of Von Willebrand's disease. The Factor VIII activity of 45% is similar to previous assays
18/11/1975	letter Dr GRO-D, Consultant Haematologist Harrogate to client – As an additional facility for patients with bleeding disorders we have started to hold stocks of cryoprecipitate at Harrogate General Hospital and we are working in conjunction with the haemophilia centre at Leeds.
3/10/1978	GP note. Sore throat & cough. Coughed blood yesterday. Needed cryoprecipitate at hospital. Seen by Dr GRO-D
4/8/1980	letter Dr GRO-D to Dr Swinburn. She has been troubled with recurrent haemoptysis since May 1977… On May 1979 until now she has been well and as far as I know her only episode of haemoptysis involved a single injection of cryoprecipitate and a course of Cyklokapron some three weeks ago.

19/8/1980 referral from Dr Swinburne to Dr Charley Chest Physician Leeds. 12 episodes of bleeding thought to be in the pharyngeal region, which have been treated with Cryoprecipitate together with Tranexamic Acid. Also symptoms of breathlessness with wheeze.

2/10/1981 letter David Taylor Gynaecologist and Obstetrician to Dr Chayda Purnell. On examination I agree with you she has a very nasty cervicitis... I have arranged for her to have this cauterised under a general anaesthetic next week. She will need an injection of Factor 8 to begin with I have arranged for this to be given by Dr GRO-D.

13/10/1981 letter David Taylor Gynaecologist and Obstetrician to Chayda. Further to my letter of 2nd October, your patient had a radical cauterisation of cervix performed on the 6th October. Factor 8 was given prior to the surgery and she was discharged on Tranexamic acid 500mg.

8/4/1982 letter Dr GRO-D to GP. Her blood count was normal, a Factor VIII level at 44 percent, no inhibitors, no evidence of hepatitis and normal liver function studies

Sept/Oct 1982 handwritten notes on lined paper - had cryo for a bleed from the throat. Had a dose of cryo at Harrogate. Had hepatitis 7 weeks later. Followed by bronchitis, pneumonia and pleurisy. Had 1/12 in bed followed by breathing exercises. Now complaining of sickly taste in the mouth. Aching in Rt flank. Dizzy spells & stiff neck... HBs Ag antibodies

21/9/1982 given 1,000 u FVIII concentrate HCB 2952 for Haemoptysis

10/11/1982 ? hepatitis

13/11/1982 Jaundice ++. Hep A –ve, Hep B –ve. Non A Non B Hepatitis. Discussed with patient & Dr GRO-B Reported to Oxford (22/11/82) Needs – repeat LFT early December

18/5/1983 letter Dr Swinburne to Dr GRO-D. I have reviewed her hepatitis status and will let you know the results when they are available. Most of her symptoms are being aggravated by the shared anxiety they both felt following her illness last year. I reassured them strongly on most points, but cannot guarantee that this will have much effect. One of her problems was that she would get 'AIDS' from her cryoprecipitate and she was glad to hear it was a local product!

8/6/1983 letter Dr Swinburne to client – your blood tests show that you are not immune to Hepatitis B and vaccination is advisable

11/7/1984 letter Dr GRO-D to GP. I was a little concerned to see that her blood test results are still abnormal with raised liver enzymes and a reduced platelet count. The liver enzymes are a reflection of the chronic liver changes brought on by the Non-A, non-B hepatitis that she had two years ago and the platelet count is unexplained … The significance of the disturbed liver function tests is uncertain, but is, unfortunately, not uncommon amongst patients who had Non-A, non-B hepatitis after Factor VIII concentrate. At present we have no way of knowing whether the change is life-long or even of clinical importance

3/6/1985 letter Dr GRO-D to GP. I am happy to say that she has had a more or less trouble-free year with some bruising and slight haemoptysis that responded to treatment with Tranexamic Acid without needing blood products. She has been screened for the HTLV-III (AIDS virus) and is negative

15/7/1987 Dr GRO-D – she has had an immu… +cp for about 18 months. She is not aware of this. HIV negative

10/9/1990 letter Dr GRO-D to GP, Harrogate. I did discuss the possibility of changing from first line treatment with Factor VIII concentrate to first line treatment with DDAVP (Desmopressin). .. I will take to GRO-B again once I have all the manufacturer's instructions to hand. .. This

	treatment has been available for many years and the only reason for it being recommended now is to avoid the administration of blood products to people wherever possible in the light of the recent HIV litigation.
12/9/1990	letter Dr GRO-D to client – I now have the information concerning the use of Desmopressin… I feel it would best be given at hospital in the first instance
7/11/1990	letter Dr GRO-D to GP – I will take over her care. This lady has VWD type 2B. In this situation a drug such as DDAVP is contra-indicated and bleeding episodes should be treated with factor VIII concentrates
12/2/1991	letter Dr Muers General & Respiratory Medicine to Dr GRO-D. CT scan shows middle lobe bronchiectasis… high degree of probability that she is bleeding from this bronchectatic right middle lobe
10/4/1991	bilateral bronchogram – showed right middle lobe bronchiectasis - tubular
13/6/1991	Discussed Hep C +ve result with her & husband. For surgery Monday
15/8/1991	recovering from surgery. Husband informed as to his Hep C status (neg) & LFTs
16/8/1991	letter Dr GRO-D to GP. Successfully recovering from recent lobectomy. She is Hepatitis C antibody positive most likely related to an episode of hepatitis she had many years ago. Her LFT are virtually normal and I have tried to reassure her that in my opinion nothing further needs to be done about this particular at this time, but I will continue to monitor her LFTs once or twice a year. I have checked her husband and his Hepatitis C antibody test is negative and his LFTs are quite normal.

28/3/1995	letter Dr GRO-D to GP. I did bring up the matter of Hepatitis C infection and GRO-B knows that she has been exposed to this virus in the past. The cause of this would have been the coagulation products she has received and virtually all my patients' who have repeatedly received blood products over the last 20 years are now Hepatitis C positive. GRO-B LFTs are mildly abnormal (80), which is about twice normal. So there is a suggestion that there may be some hepatic inflammation present.
4/7/1995	letter Dr GRO-D to GP. She is Hepatitis C antibody positive and Hepatitis C RNA positive
16/1/1996	letter Dr GRO-D to GP. The outstanding problem … is the fact that she may have chronic Hepatitis C: her serology is positive. Interestingly, her last two LFTs were normal
23/4/1996	her LFT's periodically taken over the last 12 months have all been quite normal
26/11/1996	her last LFTs were 85, which was about twice normal and that was a little unusual for her
20/2/1997	her LFTs remain persistently mildly abnormal. Her hepatitis C PCR quantitative test was present at quite a high level
28/5/1997	letter Dr GRO-D to GP. In February her LFT were normal and her Hepatitis C PCR test had fallen from 900,000 to 300,500. What all this means is anybody's guess. However, the general feeling is, so long as LFTs remain normal and the PCR test is not progressively increasing with the passage of time, then, most likely, nothing terribly significant is going on in a patient's liver

22/8/1997	her LFT remains minimally distrusted with an ALT of 36 (upper limit normally 35). Her PCR test is swinging all over the place and certainly I cannot detect any particular trend from these results
26/1/1998	letter Dr GRO-D to GP. She is aware that 80% of patients with this infection do not come to grief
10/5/1999	Dr GRO-D not prepared to suggest liver biopsy. He recommends combined therapy
15/2/2000	patient unwilling to undergo liver biopsy. Discussion about Interferon treatment but patient declined lengthy course of treatment that has no guarantees and believes there will be a cure in 10 years
8/4/2002	episode of haemoptysis due to minor flare up of bronchiectasis
13/11/2002	patient concerned about her Hepatitis C treatment and the problem with her low platelet count (25-40) which possibly will make treatment for her Hepatitis C infection very difficult indeed
12/3/2003	3,000 units for factor Haemate P prior to a hysteroscopy
7/11/2003	Hepatologist's in 2 minds about treatment for Hepatitis C because of her low platelet count (49) which probably would go significantly lower on Interferon treatment
15/7/2004	gum bleeds on a daily basis. Suggested Tranexamic Acid 1gm tds. Given Tranexamic Acid mouthwash
7/9/2004	Patient vCJD exposure assessment form
20/9/2004	letter from GRO-D to patient with information about vCJD

10/1/2005	further letter from GRO-D to patient confirming that she did receive a factor concentrate manufactured from UK-sourced plasma during the at risk period (1980 – 2001) therefore she is considered 'at-risk' of vCJD for public health purposes
27/7/2006	recurrent nose or throat bleeding and oral thrush
8/2/2008	significant large bleed which affected her lung. Recurrence of haemoptysis related to flare up of her bronchiectasis
18/6/2008	she is mulling over the idea of being treated for Hepatitis C
2/3/2009	lung nodule scare.
19/3/2009	lung nodules not lung cancer
7/9/2009	with regard to her liver disease, she has decided against treatment for Hepatitis C as long as her bronchiectasis is troublesome and I would agree with that – Dr GRO-D
24/5/2010	Nov 2009 haemolysis (bleeding) of relatively small volumes
1/11/2010	bouts of nose bleeds. Referred to Leeds ENT
9/11/2010	18 admissions for nose bleeds. Prominent vessels in right Little's area (in nose) suitable for cautery
1/2/2011	cauterised right side. Will cauterise left side
25/2/2011	fibroscan - medium liver stiffness of 5.2KPa which are below even the moderate fibrosis range. This is of course very reassuring
5/3/2012	letter Dr Lishel Horne to Dr C Millson – we now have evidence that she does have type 2B VWD

12/3/2012	Hepatitis C genotype II
14/3/2012	Fibroscan Newcastle 4.3KPa. This is a low score suggesting no fibrosis. It certainly excludes any significant fibrosis
30/7/2012	patient is a little in two minds about where to go ahead with eradication treatment for her hepatitis C
23/8/2012	seen by Dr GRO-D, Consultant Hepatologist. Interferon free regimes might be 2015, but it could be a good deal longer, or less. She may only require 12 weeks of interferon therapy. Mild liver disease. Arranged further fibroscan March 2013
3/2/2013	letter from Dr Horne – I note that she wishes to defer treatment for Hepatitis C in view of her recent favourable fibroscan results
6/8/2013	her husband administers Haemate P at home now
21/10/2015	letter Dr Horne to Dr GRO-D – I would be very grateful if you would consider keeping GRO-B hepatology follow up in Leeds as she is registered at Leeds Haemophilia Centre. It helps us greatly for our patients who have contracted hepatitis C from contaminated blood products if there liver follow up is in the same hospital as their haemophilia follow up
1/3/2016	I have started her on a low dose of Ribavirin. 200mg bd for 1 week. If she tolerates this and does not have any bleeding we will increase to 400mg bd on 8/3/2016. … We hope to get this lady through her 12 week course of treatment consisting of Sofosbuvir, with the addition of Ribavirin
8/3/2016	last week she commenced on Sofosbuvir 400mg tablet once a day, and Ribavirin 200 mg bd. Complaint of some nausea

10/5/2016	10 weeks into a 12 week course. She is tolerating this really well and her last viral load has been negative