Witness Name: GRO-B

Statement No: WITN1029001

Exhibits: WITN1029002 – WITN1029004

Dated: 30 April 2021

INFECTED BLOOD INQUIRY

STATEMENT OF GRO-B

I, GRO-B GRO-B with an address of GRO-B GRO-B will submit as follows:

Section 1: Introduction

1. I am a 64 year old man who suffers from a severe form of Haemophilia A with a blood clotting factor VIII of less than 1%. As there was no known family history of this medical condition, I was not diagnosed with having Haemophilia until shortly prior to my second birthday in 1958. I had an 18-month younger brother with the same severe form of Haemophilia A, who was diagnosed shortly after his birth in December 1958.

Section 2: How infected

2. In the early to mid 1960's I recall a lot of our childhood was spent in and out of hospital because at that time there was no effective treatment available for joint swelling and other haemorrhage's and bleeds that we suffered growing up.

3. By the age of 10 and as far as I could remember at that time, I had stayed in hospital 36 times during my childhood. Treatment at that time was initially by blood transfusion and then (from about 1962) by plasma transfusions followed eventually by Cryoprecipitate from about 1966.

4. I developed a severe reaction to Cryoprecipitate in 1974 and so to avoid this, my brother and I were started on freeze dried Factor VIII ('Hemofil') for which we had to attend the casualty department of our local hospital in GRO-B for this to be administered as and when needed, but we had been told by our Haematologist consultant in GRO-B that this was quite expensive and that there was a chronic shortage of supply.

5. I left home to live in GRO-B as a student in September 1974 and my care and treatment was transferred to the GRO-B Haemophilia Centre at GRO-B Hospital, where I have attended regular appointments ever since. It was in or about 1976 that I was shown how to administer Factor VIII myself and from that time onwards I have been on 'home treatment'.

6. It was towards the end of my time studying at GRO-B (1978) that I first became aware of the AIDS (later to become known as the HIV) virus in the USA and I read in various newspapers and periodicals held in the college library, that because the UK was not self-sufficient, the NHS had to import commercial factor VIII from the USA.

7. I was particularly aware and concerned that this imported commercial product was derived from 'paid for' blood donors who might have been at risk of being exposed to the AIDS virus. In this respect I collected and still have originals of a number newspaper articles published on AIDS dated between 1985 and 1987. I also have various original Haemophilia Society published literature dating back to 1984, including a 'Haemofact' leaflet ('Release No 5') on AIDS published by the Haemophilia Society in December 1984, which included quotes from the appointed Minister at the time (John Patten) who stated that 'heat treated' products would be available from Elstree in April 1985 and that the UK 'will be self-sufficient in blood products from 1986'. The leaflet also

endorsed *"earlier advice to everyone with Haemophilia, however mildly affected, to continue to accept medication as prescribed by medical staff..."* I have attached a copy of this leaflet and refer to **Exhibit WITN1029002**. I have other original documents that might be of interest to the Inquiry that I would be please to provide copies of these including AIDS leaflets published by the National Blood Transfusion Service in 1985 and 'AIDS And The Blood – Practical Guide' produce by Dr Peter Jones in 1985, if these documents are not already available to the Inquiry

8. Although I cannot recall the date, I clearly remember discussing the risk of AIDS and commercial Factor VIII with Dr GRO-B at the GRO-B Haemophilia Centre, who I had established a good medical relationship with until his subsequent retirement. I was told that there was very limited stock of NHS Factor VIII material available and this was being reserved for children and that only imported factor VIII was available for others such as myself.

9. I became increasingly concerned about the risk of contaminated Factor VIII and the social stigma of Haemophilia being linked to AIDs. I made a conscious decision not to use commercial Factor VIII unless absolutely necessary, although sometimes I had to relent because of the severe pain of a joint haemorrhage, but my treating doctor at the time (Dr GRO-B) put it to me that the 'theoretical risk' of receiving contaminated blood products was less than the risk of damage that I would certainly be doing to my joints if I did not use imported Factor VIII, and that not doing so would have lasting damaging effects, especially in later life.

10. Although I was later also encouraged to use commercial Factor VIII on a prophylactic basis, I have only ever used it 'on demand' and even then only if absolutely necessary. Indeed, even today, I remain reluctant to consider using modern 'safe' Factor VIII treatment on a prophylactic basis due to my inherent lack of trust.

11. I am not sure exactly when I became aware or was told that I had ***not*** been exposed to the HIV virus but in my files I have a record (proforma) that I agreed

for this to being disclosed to a medical study in September 1988. The fact that I had not been exposed to the virus made me more determined than ever not to use any Factor VIII if it was from a commercial source, and it is this determination that I believe has resulted in me remaining free of the HIV virus (unlike my brother).

12. However, as a consequence of my reluctance and conscious decision not to use commercial factor VIII unless absolutely unavoidable due to severe pain from a joint swelling or because of trauma caused by events such as a fall, I felt that I had to accept the risk of long-term damage to my joint bleeds; as to me as potential exposure to the AIDS infection posed a more significant risk and one most likely to be a fatal.

13. I lived in GRO-B as a student between 1974 and 1978, before returning to my hometown in East Sussex, although I have continued to attend the GRO-B Haemophilia Centre every six months (or occasionally on an annual basis). It was during one of these check-up visits in the early 1990s that I was casually informed by a junior doctor that I had been infected with hepatitis 'non-A non-B'. During this visit it was mentioned to me that this had almost certainly been caused by the commercial factor VIII that I had received in the past.

14. Prior to that time I had absolutely no knowledge that I had been infected with Hepatitis C or what the future consequences might be. This was a great shock to me given the considerable lengths I had previously gone to in not taking commercial Factor VIII in order to avoid the HIV infection risk.

15. Indeed, the full consequences were not explained at that time and only became fully aware to me some years later in about 1993 when the infection became known as HCV and by this time I was already married with a young child (born in GRO-B 1993). My wife was tested in 1994 and again in 1998 but she was confirmed to be clear of the HCV virus (at that time).

16. My wife and I can also recall that about the time we got married in 1986, I had a commercial factor VIII batch that was subsequently recalled as potentially

being unsafe through contamination. Unfortunately, I no longer have the letter that I was sent about this but we also recall that the 'suspect' batch numbers were very close to those of the commercial Factor VIII vials that I had stored in our fridge at that time. I had assumed this this would have been recorded in my hospital, Haemophilia Centre or GP medical notes.

17. As set out in Section 5, I have obtained and examined my medical records. I was particularly shocked when following this inspection, I found out that in a critical time in 1981, my long-standing GP had taken it upon himself to "*disregard the many routine hospital reports about his haemophilia*" when he passed on my medical records to a new GP. This is again noted by a subsequent GP in 1991 which refers to "*previous hospital letters pruned by ex-GP*". In 1997 my GP also raised a concern that there was "*a marked lack of communication from the hospitals involved in his care between 1988 and 1996*". I have attached a copy of the above and refer to **Exhibit WITN1029003**.

18. Upon examination of my records at the GRO-B Haemophilia Centre, I found a table at the back of the file that (without my knowledge at the time) showed that I had been tested for and found to be positive for HCV in October 1989. I do not know when I was actually infected with Hepatitis C but clearly this was sometime before the positive HCV test in October 1989 and from the few records that I have been able to obtain from the period, these indicate that I had a raised liver function test over 10 years earlier in August 1979.

19. The examination of my medical records also identified a significant period of missing records between 1976 and 1978 while I was studying as a student and attending the GRO-B Haemophilia Centre. This is of very great concern to me as this is likely to have been the very time that I was exposed to commercial imported Factor VIII. This is a concern further amplified by my GPs inexplicable decision to 'prune' my medical files in 1981 before forwarding what remained of my medical notes to a new GP. This was just two years after I have been reported (again without my knowledge) to have had an abnormal liver function tested.

Section 3: My brother

20. I had an 18-month younger brother with the same severe form of Haemophilia A, who was diagnosed shortly after his birth in GRO-B 1958.

21. In or around 1976, my younger brother, who trained to be an accountant, was partly under the care of his local hospital in GRO-B and partly under the care of GRO-B Hospital in London. My brother suffered from severe haemorrhages to his hips, knees and ankles throughout his teenage years which meant that he had more Factor VIII treatment than myself over this period.

22. Because of the severe joint bleeds and associated pain that my brother also suffered, he had no real option other than to take the imported commercial Factor VIII on a regular basis as there was no other form of treatment available to him. Very sadly his treatment exposed him to both the AIDS and HCV viruses and he succumbed to this and passed away with multiple organ failure in GRO-B 1995 when he was only 38 years old, leaving a wife but no children. I understand that his wife has taking up his case on his behalf at the Inquiry.

23. My mother never overcame the grief of losing her youngest child and she died of a heart attack GRO-B 1999 when just 70 years old.

Section 4: Consent

24. It will be noted that in Section 5 of this Statement, I have investigated my medical records dating back some 64 years including the critical years between the mid to late 1970 until the early 1990. At no stage was I asked for or did I give consent for both the HIV and HCV tests that were undertaken without my knowledge and although I was eventually made aware that my HIV test was negative, it was not until the early 1990's that I was told that I was HCV positive, some years after the records indicate that this test was carried out.

25. In Section 5, I have carefully set out the chronology of my medical records and the individual document sources, and I consent for these medical records to be disclosed to the Inquiry but on a private and confidential basis.

Section 4: Impact

26. My brother and I had a childhood that was severely disrupted (as were the lives of our parents) by our many trips to hospital for our treatment as a result of our haemophilia, which initially, was limited to blood and then plasma transfusions in the early to mid-1960s, followed then by cryoprecipitate during the late 1960s and early 1970s. The introduction of Factor VIII treatment in the mid-1970s changed our lives very significantly, offering a more effective form of treatment particularly after we were able to administer this ourselves at home as and when needed.

27. This had the enormous potential to change our lives (and those of other haemophiliacs) for the better, having suffered so much during our childhood, to enable us to gain qualifications due to having missed much of our education during previous years; develop a career and have a relatively normal lifestyle including getting married, having children and even taking foreign holidays for the first time, as we were able to take our medical supplies with us.

28. Instead, this turned out to be a disaster and tragedy with the use of unsafe treatment in the 1970s and 1980s that cost my brother his life in 1995 when he was only 38 years old and causing me not only the obvious distress at losing my brother but also the stigma about the public perception of the link between haemophiliacs and AIDs. This was followed by the continuous stress, anxiety and disruption to my life (and that of my family) and my career prospects caused through the hepatitis C infection.

29. This post traumatic anxiety continues with me today with the attendant risk of potential future liver cancer, and my remaining reluctance to administer Factor VIII on a prophylactic basis in case other issues 'come out of the woodwork'

such as was the case with the CJD risk first raised in 2001 after products were heat-treated and regarded as 'safe'.

30. Despite a very disrupted childhood caused by numerous hospital stays and trips to Casualty for treatment, I managed to obtain the necessary O-levels and A-levels to be able to undertake a four-year GRO-B Planning degree course between September 1974 and June 1978, at what was at that time known as GRO-B (now known as GRO-B.

31. My choice of GRO-B was partly influenced because I was told by my local Haematologist in GRO-B, that GRO-B (unlike GRO-B) had its own specialist Haemophilia Centre.

32. One of the greatest impacts on my life is that because of my concerns about potentially contracting HIV in the 1970s, I made a conscious decision not to administer commercially imported Factor VIII, against clinical advice. I have no doubt that because I did not take such treatment unless absolutely necessary, and because there was no 'home produced' Factor VIII available due to 'shortages' seemingly due to the expense at the time, I have avoided HIV infection. This action has however, resulted in the severe damage to my joints and severe lack of mobility that I experience today, which limits and affects every part of my daily life.

33. This lack of treatment that I should otherwise have administered when needed for even small bleeds, has undoubtable severely affected my current level of mobility and ability to be able to take on relatively simple tasks such as using stairs, rising from seats without arm rests and walking and even standing for more that short periods due to weak and damaged elbows, ankles, knees and wrist joints and associated pain. Not being able to bend my knees causes considerable problems attending any format events, as I can only sit (uncomfortably) on end of aisle seats with my legs sticking out into staircase/passageways, unless specialist disabled facilities are available. There are similar problems when travelling by bus, train or plane.

34. I think it was in my mid 20s that my left knee became locked in a bent position followed by my right knee in my early 30s. Despite periods of having both knees in traction during different occasions requiring hospital stays, this was ineffective and I now only have a limited range of movement in all my joints apart from my shoulders and hips. In more recent years I have also suffered from lower back pain due to my poor posture cause by my fixed and bent knee joints when walking/standing.

35. I also have a great concern that having made a conscious decision to avoid administering commercial factor 8 as far as possible, and risking future joint damage, I still became exposed to hepatitis C directly as a result of this unsafe treatment. I was staggered to note from obtaining and inspecting my medical records that as long ago as 1979, that I was recorded as having an elevated liver function test, confirmed again in 1984 with this eventually being diagnosed as being hepatitis C by a blood test at the GRO-B haemophilia centre in 1989 (although I was not made aware of this until years later in about 1993, after or about the time of the birth of my son).

36. Towards the end of 2000, I was becoming increasingly exhausted and tired when driving from home for an hour or so each way to my job in GRO-B where I had worked for eight years. In 2001, I made the very difficult decision to leave a well-paid position at a Director level with a final salary pension scheme, to set up my own company in order to be able work from home. This was obviously a huge risk given my hepatitis C infection and its associated complications and that I had a young family, mortgage etc.

37. Due to the future uncertainty about my health prospects, I decided not to employ any professional staff (other than secretarial staff). This undoubtedly increased my work pressures and limited any prospects for company expansion and advancement, unlike a work colleague who, at the same level and at the same time, left the same company to also set up his own business and has since taken on professional staff to expand his company which has since been very successful. While I would regard my company as having been successful,

I feel that it could also have been more successful had it not been for my HCV health issues and the associated lack of future health confidence to be able to expand the company by taking on professional associates and staff.

38. I had a liver biopsy in July 2002 as I was informed that this was essential before I could commence any treatment to try and clear the HCV virus. I remember clearly that this procedure, without any anaesthetic or sedation, was one of the most painful experiences of my life, and I have been well used to suffering severe pain from various, often previously untreated joint haemorrhages. The results confirmed that my liver had been badly damaged by the HCV infection but had not thankfully, reached ‘end stage’ liver disease.

39. I commenced combination treatment of Interferon and Ribavirin in 2003, but only for a period of six months rather than a year because there was no change to my virus status, and I remained infected. This aggressive treatment had serious side effects that severely affected my ability to run my company.

40. My family were also concerned about my apparent ‘mood swings’ during treatment and, as a result of this treatment, I not only developed severe psoriasis on my scalp (which has continued to this day) but I suffered various skin reactions which led to lesions and bleeding from them staining bed sheets, pillows, towels and clothing, etc.

41. My wife is a type 1 diabetic and at that time, she would very regularly prick her finger in order to test and monitor her blood sugar levels. We think that as a direct consequence of my bleeding lesions and her finger pricking, she also became infected with Hepatitis C, having previously been tested and been shown clear in both 1994 and 1998. This was despite her being paranoid about cleanliness and not letting herself, or the children anywhere near any blood stains from my skin lesions. Sadly we had to accept that when you are asleep, this vigilance is not possible. Initially a blood test indicated a positive result in late 2005 after she had become very unwell with acute hepatitis symptom. Then a blood test confirmed a ‘zero conversion’ in January 2006, and she was told she was one of, around 28% of people, whose immunity has cleared the

virus. Then in 2014, after hearing a radio 4 programme where a medic described how viruses can hide in organs then re-emerge, she asked her GP to test her again. He was reluctant, but she managed to persuade him and then to our horror she was confirmed as HCV positive in 2014. Once back at the hepatitis clinic, we were told that the viral blood testing process had become more advanced so it could detect lower levels of the virus than in 2006, so it was-probable that she had continued to have been infected since being first confirmed positive in 2005.

42. Given the very significant impact the infected blood products disaster not only on my life, my brother's life and my family life including that of my wife, she will also be producing a witness statement to explain the impact and stress on her life and that of our two children, and not least our constant worry and concern about potentially passing on our hepatitis C infection to them as a result of blood transfer through either me cutting myself or my wife's finger pricking as part of her diabetic control.

43. This stress was increased by the considerable uncertainty about how the infection might be passed on given that to this day we cannot be entirely certain as to how my wife became infected, given the considerable precautions that we had taken, which were subsequently proved to be ineffective.

44. I wish my identity to remain confidential for various reasons, I nevertheless wish to make my experience and evidence known to the Inquiry as I feel that because of my fortunate early knowledge about the AIDS virus in the USA, and possible link to contaminated blood products, I had made a conscious decision not to administer any imported commercial Factor VIII concentrate unless absolutely necessary.

45. Although this has undoubtably now led to me having severe joint damage in later life, I did not acquire the AIDS virus, unlike my brother who is now, as a direct result, is no longer with us. Even though I made a conscious decision to avoid commercial imported Factor VIII as far as possible and unless absolutely essential with no alternative available, I still was exposed to commercial

imported Factor VIII that led to me contracting the Hepatitis C virus with its associated liver damage and its wider consequences.

Section 5: Medical Records

46. Between September 2018 and November 2018, I requested and inspected my medical records and obtained photocopies of my medical history from my GP (dating back to 1958) and from the GRO-B Haemophilia Centre that I had attended since 1975 (although the correspondence dates back to 1974). This was mainly to ascertain when and how I acquired the Hepatitis C, which I only became aware of during the early-1990’s. I have also obtained my medical records from the GRO-B Heath Care NHS Trust. I have collated these in date order with my own records of letters etc. that I received. I have made a note of the individual document sources which I am content for all of the medical records to be disclosed to the Inquiry (although not to them being made available for public inspection). Accordingly, I have attached a copy of these records and refer to **EXHIBIT WITN1029004.**

47. The following summary of these records are of interest and significance in my opinion (note; - the reference to GRO-B’ relates to correspondence from the Haematologist at the GRO-B Hospital at GRO-B; the reference to GRO-B’ is correspondence from the GRO-B Haemophilia Centre: the reference to GRO-B (GRO-B) relates to the Hepatitis treatment and the reference to ‘GP’ is correspondence relating to various GP’s that I have been registered with over the period referred to);

- 04.11.74 letter GRO-B to GRO-B; A request for me to have ‘concentrated AHG’ due to my reaction to Cryoprecipitate.
- 02.12.74 GRO-B response suggesting that both my brother and I should be on a ‘freeze-dried preparation of factor VIII’ to avoid the reactions experienced but *“We have a chronic shortage of factor VIII concentrates at this Centre”* with a recommendation that the Lister Institute at Elstree is contacted direct to see if supplies could be made available for my brother and I. The other possibility was to purchase ‘Hemofil’ from the

Travenol Laboratories in Norfolk *"provided your local hospital budget can stand it"* as *"It is very expensive*".

- 18.02.75 GRO-B to GRO-B – They have contacted the Lister Institute but still waiting for a response. *"we are also looking into the commercial material from Travenol"*
- 18.02.75 GRO-B to GP – Still trying to get 'freeze-dried Factor 8' for my brother and I but they have *"not really been able to get definite continual supplies as it is rather in demand"* and in the meantime we should receive Cryoprecipitate at the hospital's casualty dept.
- Sometime post April 1975 (my 19th birthday) – GRO-B provided me with a letter to take to Casualty when I needed to attend to explain my allergic reaction to Cryoprecipitate and that I should have 'Haemophil' instead.
- 09.02.76 – GRO-B medical note of my hospital stay in the GRO-B Hospital at GRO-B from 03.02.76 when I had *"two days of human AHG infusion".* As I had no control over the treatment that was administered, I do not know the source or nature of the AHG infusion given
- 09.10.76 – GRO-B second hospital stay from admission on 04.10.76 and given 'Factor VIII concentrate'.
- No records available for 1977 or 1978.
- 03.08.79 GRO-B to GRO-B – by now I had left GRO-B to return to East Sussex and the letter related to GRO-B taking over my treatment. The letter confirmed that I had been on home treatment since 1976. The letter also confirmed a recent liver function test showing a moderately elevated AST level and asking GRO-B to monitor this.
- No records available for 1980.
- 24.02.81 GP to new GP who had requested my medical notes This states *"They are thinner than you would expect as sometime ago I went to considerable trouble to discard the many routine hospital reports about his haemophilia but I am sure you will find the essential information there"* .
- No records available for 1982.
- 01.09.83 GRO-B to me enclosing medical treatment supplies *"which on this occasion is factor VIII made at Elstree. It may, on occasions,*

however be necessary to send you Commercial factor should our stocks of Elstree material become low".

- 10.01.84 GRO-B confirming support for my Mobility Allowance application.
- 23.11.84 GRO-B to GRO-Bn relating to the traction to my (left) knee.
- 04.12.84 GRO-B to GRO-B confirming that I had attended the GRO-B Haemophilia Centre since 1975 and been on home treatment since 1976. It confirms that in recent years I had been receiving 'Koate' or NHS factor VIII "*depending on the state of our supplies".*
- 20.12.84 GRO-B to previous GP (as I had sought the local supply of factor VIII rather than this being sent by GRO-B). This letter also confirmed that a liver function test revealed *"a mild elevation in the asparate transaminase such as may be seen in haemophiliacs on regular treatment with Factor concentrates*".
- 1985 -1987 No records available.
- 18.04.88 Completed insurance form on GP file confirming care at GRO-B but *"no letters since 1984."*
- 05.09.88 proforma confirming my agreement to allow my negative HIV tests being made available for a study.
- 16.09.88 GRO-B to current GP which confirms that I was receiving Factor VIII from them (not GRO-B) although I was still attending 6 month check-ups at GRO-B.
- 04.10.88 GRO-B to GRO-B after my follow up appointment in March 1988. It confirmed that I was using NHS factor VII. It also confirmed my negative HIV status but anti Hbs positive with Hbs AG not detected. It mentions that my liver function test was normal.
- 01.12.88 GRO-B to GRO-B - prophylactic factor VIII being considered but introduction delayed.
- 16.10.89. Letter for GRO-B to 'Whom it may concern' confirming that I am "*HIV antibody negative and likely to remain so".*
- 30.10.89. In looking through my GRO-B file I found at the back a schedule of all my blood tests results over the period between 03.02.1976 and 16.12.1996. An HCV antibody entry appears for the first time on 30.10.89

and the same result continues up to the last test recorded in December 1996. I had no knowledge of this at that time and was not advised of the results.

- 1990 No records available
- 03.04.91 GP medical notes - There was an insurance form completed by my then GP confirming "*previous hospital letters pruned by Ex GP*" and a second completed insurance form dated 12.08.91 from my GP notes in relation to a mortgage protection policy that I was confirmed as negative for HIV when tested in 1984 and 1986.
- 08.12.92 From my GRO-B file I obtained a completed proforma of a follow up appointment. This in itself is not unusual but there would normally be a letter sent to my GP providing a record of the follow up appointment but there was no such letter on the file (nor in my GP records).
- 30.03.93 GRO-B n to me advising of the general trend to produce more pure factor concentrates "*to eliminate unnecessary contaminates*" and that the in the South East Thames Region it had been recently agreed to use only high purity products but "*Because there are licencing problems with these locally produced "NHS" materials produced by Bioproducts Laboratory the factor concentrates this year are being bought from commercial sources…*
- 03.07.93 I send a fax to GRO-B expressing concern about only commercial factor VIII being available from GRO-B and asking for advice. I have evidence that the fax was sent but I did not find this when I inspected my GRO-B medical notes and I have no record of a response.
- 1994 No Records available.
- 16.03.95 GRO-B; Completed proforma on file entitled 'Hepatitis C Checklist. This was completed by GRO-B' Who I assume was a medical member of staff. The form has a 'tick box' saying *'The patient was already aware of his result'* (i.e. positive for HCV).
- 15.01.96 GRO-B Blood test states HIV negative but *"Previous HVC result Positive (8/12/92)".*
- 17.01.96 GRO-B to GP. Letter after follow up appointment which confirms at that time I was having annual follow up appointments and my Factor

8 treatment was 8Y. The letter also states in commenting on the blood test results *"He therefore shows a mildly abnormal liver function tests, possibly related to his chronic hepatitis C".*

- 25.01.96 GRO-B to GRO-B Letter enclosing. *"* GRO-B *Factor VIII issues for 1995. As you will see he has been receiving 8Y exclusively, and he has had this product for many years at his own request".* The letter goes onto ask advice on whether I should receive other forms of Factor 8.
- 01.02.96 GRO-B to GRO-B responding to GRO-B letter. Suggestion that I should no longer attend GRO-B follow ups on costs grounds.
- 01.03.96 GRO-B to GRO-B response noting that I might be reluctant to be seen at GRO-B, but again asking for a response to a previous request regarding my recommended Factor 8 treatment.
- 13.03.96 GRO-B to GRO-B response confirming *"I would certainly continue to treat him with 8Y at present. Our general policy at present is to use recombinant factor VIII in children under 10 and high-purity plasma-derived concentrate (Replenate) for HIV positive individuals or the few patients who have had an allergic reaction to 8Y."*
- 19.12.96 GRO-B to GP with letter after follow up appointment confirming that I am on 8Y home treatment and the *"He has had some difficulty with this factor VIII supply due to the fact he is the only haemophiliac in the* GRO-B *County Hospital in* GRO-B *who is on intermediate purity products at the moment, which often makes him short of supplies".* The letter adds *"I had a long discussion with* GRO-B *about his liver function state at the moment, since as you know he has chronic hepatitis C virus infection with a persistently detectable RNA and marginally abnormal liver function tests"* and this continues *"He has no clear signs of chronic liver discase but his liver was palpable about 1cm below the right costal margin and in the epigastrium. These findings are consistent with an ongoing hepatitis C but we cannot be certain about the state in which his liver discase is at present since it is not our policy to perform liver biopsies routinely in haemophiliacs".* The letter also confirms that by this time I am back on 6 month follow up appointments.

- 10.04.97 GP to GRO-B about possible Interferon therapy. Note says that I was told about the Hep C infection *"last year"* i.e. 1996 and adds *There is a marked lack of communication from the hospitals involved in his care between 1988 and 1996. We have no letters from them so I am not entirely certain when this was diagnosed.*
- 08.07.97 GRO-B to GP which states "*We have discussed Interferon therapy at length* [with me] *and basically I have told him that we need to know exactly what his Hepatitis C status is. Interferon will be indicated if he is RNA positive and to establish what genotype he is. As a haemophilic we can proceed to Interferon therapy without a liver biopsy as the risk of this far outweighs it's benefits".* This treatment would be stopped after 3 months if no response is shown.
- 22.08.97 GRO-B to GP confirm in HCV positive status and whether to treat with Interferon on a blind basis without a liver biopsy.
- 04.09.97 GRO-B to GP confirming that I opted to have treatment without a biopsy.
- 18.09.97 Me to GRO-B suggesting possible treatment start dates.
- 07.10.97 GRO-B to GP Treatment due to start on 03.11.97
- 11.11.97 GRO-B to GP confirming that I had decided not to undergo treatment as I was advised that might then prejudice the effectiveness of combination treatment with Interferon and Ribavarin when this became available in the future.
- 14.11.97 GRO-B to GP confirming blood test result.
- 08.12.97 GRO-B to GRO-B confirming that I am the only person in the area to be receiving 8Y Factor *"at his own request as he is reluctant to change to commercial supplies"* and requesting advice due to a new variant CJD risk. The letter confirms that at that time in GRO-B others were being supplied with a combination of Aplhanate and Monoclate, and added *"We have yet to be approved by East Sussex Health Authority the extra funds for recombinate Factor VIII".*

- 22.12.97 GRO-B response to GRO-B and letter states;

GRO-B

- 31.12.97 GRO-B to me with an appointment to discuss my Factor VIII treatment.
- 10.02.98 GRO-B to GRO-B following my appointment. This states;

GRO-B

- 03.03.98 GRO-B to GRO-B with blood tests results after regular follow up appointment.
- 12.03.98 Me to GRO-B confirming that I wish to postpone Hep C treatment.

- 31.03.99 GRO-B to GRO-B confirming that GRO-B were suppling me with Alphante and confirming that I wish to continue with follow up care at GRO-B perhaps on an annual rather than 6 month basis.
- 08.04.99 GRO-B to GRO-B and GRO-B to me confirming annual review and next appointment date.
- 28.05.99 GRO-B to GRO-B after follow up visit confirming that I am using Alphanate on an 'on-demand' (rather than on a prophylaxis basis); that I have been exposed to Hepatitis C in the past and that I am aware of the result; that I have raised liver function tests; My wife was tested for HCV in Feb 1998 and found negative and that I have not been exposed to the HIV virus. There was also a letter from GRO-B to me on the same date after my follow up appointment.
- 09.06.99 GRO-B to GRO-B indicating my concern about the rise in my liver function test with a recommendation for me to see a liver specialist.
- 11.06.99 GRO-B to me but not relevant.
- 25.08.99 GRO-B to GP regarding Hep C treatment and confirming home treatment with Alphanate as required.
- 14.10.99 GRO-B to me enclosing blood test results and stating that my liver function tests remain high and also that as Alphanate is currently I would be supplied with Replenate*, "which is manufactured in this Country but from non-UK source plasma".*
- 29.10.99 Not relevant (pending elbow operation).
- 04.07.00 GRO-B to GP about my concerns about my continuing liver dysfunction and confirming that Hep C genotype 1B had been identified earlier in 2000 and my continuing raised liver function tests. Letter also explains issues relating to a potential liver biopsy and risks associated with this.
- 28.04.00 GRO-B to GP with Factor treatment in April and May 2000.
- 20.09.00 GRO-B to GP mentioning that *"a liver biopsy is essential before any* [Hep C] *treatment can be initiated"* and that this had ben explained to me.

- 22.01.01 GRO-B to all patients to explain the CJD risk resulting from a positive blood donor used in factor VIII products in 1997 and 1998 but that the patients contacted did not receive any implicated batches.
- 14.02.01 GRO-B to me confirming that I had not been exposed to CJD infected supplies and the same letter was sent to GRO-B.
- 29.04.02 GRO-B to GP after follow up appointment and confirming my agreement to a liver biopsy prior to consideration of anti-viral therapy.
- 30.04.02 GRO-B blood test result confirms *"Hepatitis C Genotype; 1b"*
- 09.08.02 GRO-B to me confirming my liver biopsy results showing 'scaring' but not 'end stage liver disease' and recommending treatment with Interferon and Ribavirin.
- 12.08.02 I attend Liver treatment clinic at GRO-B.
- 23.09.02 GRO-B to me offering to discuss liver biopsy result and arranging for treatment at GRO-B.
- 10.12.02 GRO-B to GP following clinic appointment confirming my liver biopsy showed 3 out of 6 fibrosis which *"He clearly picked up from haemophilia"* and suggesting treatment with Pegylated Interferon and Ribavirin early in 2003 for a 12 month period but only 6 months if no response.
- 18.12.02 GRO-B to GP confirming that the treatment would start on 09.01.03.
- 2003 No medical records.
- 20.09.04 GRO-B to me about possible risk of CJD infected blood products between 1980 and 2001.
- 21.09.04 GRO-B to GP stating that I fall into an CJD at risk group (notwithstanding the previous advice in 2001 was that I had not been exposed to any such risk).
- 28.06.05 GP to GRO-B which states;

GRO-B

- 20.09.05 GRO-B to GRO-B confirming outcome of 2002 biopsy and subsequent unsuccessful Hep C treatment.
- 23.09.05 GRO-B to GP after follow up appointment confirming that in August 2005 my treatment changed from plasma derived Replenate to on demand treatment of recombinant factor VIII Helixate. Persistent skin lesions and psoriasis could be cryglobulinaemia secondary to Hep C infection.
- 11.07.06 GRO-B to GP following Hep C clinic review and that I remained under the dermatologist for management of psoriasis felt to be introduced by anti viral therapy.
- 2007 – 2008 No medical records available.
- 19.10.09. GRO-B to GP after follow up appointment.
- 11.11.09 GRO-B to GP further letter after follow up appointment. Confirms that I am using Advate Factor VIII on demand.
- 20.04.10. GRO-B to GP after follow up visit. This confirms that treatment is to be changed to Refacto AF.
- 20.10.10 GRO-B to GP after follow up visit confirms change from Advate to ReFacto AF.
- 12.05.11 GRO-B to GP after follow up visit confirms ReFacto AF treatment.
- 14.11.11 GRO-B to GP after follow up visit confirms Hep C positive.
- 20.06.12 GRO-B to GP after follow up visit refers to start of Hep C treatment (i.e. the second course of Hep C treatment).

- 11.12.12 GRO-B to GP after follow up visit confirms due to start Hep C treatment with Pegylated Interferon, Ribavirin and Telaprevir in Feb 2013. letter confirms that I remain unkeen to taking Factor VIII on a prophylactic basis.
- 03.01.13 GRO-B to me but nothing relevant.
- 20.03.13 GRO-B to GP confirms chronic Hep C and due to start second course of treatment.
- 01.08.13 GRO-B to GP confirming that Hep C treatment started and the development of a florid skin rash 6 weeks after treatment. I request annual check-ups due to the impact of time on my work commitments.
- 27.08.13 Me to GRO-B making a formal request to change to annual follow up appointments.
- 03.09.13 GRO-B to me agreeing annual appointments (although since 2017 this has been changed back to 6 monthly appointment).

48. I have other records after this date but these are unremarkable with the exception that I had the second course of Hep C treatment for a year (2013 - 2014) which included remaining alcohol free over this period and requiring regular blood tests (initially weekly) but the treatment was again unsuccessful. It was explained to me that because I had been exposed to the Hep C Genotype 1b (which I was also told was common for Haemophiliacs exposed to infected Factor VIII) this was the hardest type to clear through the treatment available at that time. My wife had the same genotype when she became infected with the hep C virus.

49. For many years I have had liver scans every 6 months, regular blood tests and associated appointments and these have continued to this day, as my liver remains cirrhotic and I remain at risk of developing liver cancer.

50. I have remained on home treatment with ReFaco AF on demand and although in August 2016, I was initially offered an Oxford trial for a an alternative form of treatment (ACE910) involving subcutaneous rather than intravenous injections with Factor VIII), this offer was subsequently withdrawn when it was considered

to be unsafe because of the extent of my liver damage caused by Hep C. Therefore, my damage liver has also affected my opportunity to have advance treatment that could potentially be more effective and avoid the need (and potential permanent vein damage) of intravenous injections.

Section 6: Conclusions

51. I have also made a note of the individual document sources, which I consent for these medical records to be disclosed to the Inquiry (albeit on a confidential basis).

52. Furthermore, I have certain crucial documentation in existence relating to the investigation by the Inquiry. That detail is not lightly indicated as it is based upon 25 years of investigating the circumstances surrounding the contamination of blood and blood products.

53. I invite the Inquiry to draw its own conclusions from the lack of my medical records during what seems to have been a critical period and in particular, when and to what extent medical practitioners, clinicians and others were aware of the Factor VIII treatment risks and when, having become aware of these risks, this information was passed on to those affected such as myself who potentially and unknowingly could have exposed others to this risk.

54. Indeed, how did it come about that the introduction of a new treatment that could have radically changed and improved the lives of Haemophiliacs such as myself and my brother for the better, should instead have turned into a tragic disaster costing many lives (including that of my brother) and associated family trauma as well as the devastating continuing effects for those of us who have survived?

Statement of Truth:

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

Dated the 30 day of APRIL 2021 ~~2020~~ .

Signed: GRO-B

GRO-B