Witness Name: GRO-B
Statement No: WITN5650001
Exhibits: WITN5650002-3
Dated: April 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I GRO-B, will say as follows: -

Section 1. Introduction

1. My full name is GRO-B. I was born on GRO-B and I live at GRO-B GRO-B

2. My husband, GRO-B and I have been together for 38 years and married since GRO-B. GRO-B was infected with the Hepatitis C Virus (HCV) through contaminated blood products. GRO-B has provided his own Witness Statement to the Inquiry (GRO-B). I refer to his Statement throughout my Statement.

3. This witness statement has been prepared without the benefit of access to GRO-B's medical records. GRO-B **spoke to a member of the Haemophilia staff (Nurse GRO-B) at his annual routine telephone appointment on 7th October 2020**

and was given some limited information but was also informed that a lot of his medical notes had been destroyed in the mid-1980s.

Section 2. How infected

4. GRO-B has mild Haemophilia A, diagnosed at 18 years old.

5. He was treated at the Leeds Haemophilia Centre at the St James University Hospital, initially under the care of Dr Swinburne and then Dr McVerry.

6. I refer to Exhibit WITN5650002 being a copy GRO-B s UKHCDO Haemophilia Database Records. GRO-B was treated with FVIII (BPL) and Oxford FVIII in 1981, 1983 and 1984. Nurse GRO-B (as referred to at paragraph 3 above) has provided GRO-B with the requisite product batch numbers as set out as follows:-

16-7-1981 - - - - Batch Number - HL2784 - - X 2
17-7-1981 - - - - Batch number - HL2784 - - X 2

10-5-1983 - - - - Batch Number - HLA3024 - - X 2
18-5-1983 - - - - Batch Number - HLB2954 - - X 2
06-8-1983 - - - - Batch Number - HLA3024 - - X 2

20-6-1984 - - - - -Batch Number - HLB3104 - - X 3

7. We were not given any information or advice of any risk or possibility of infection from FVIII concentrate (FVIII) at any time.

8. We were informed in 1999 by Dr McVerry at a routine haemophilia appointment that GRO-B was infected with HCV. There is an entry on GRO-B s notes that blood samples were taken for testing (for HCV and other things) on 18th February 1999 with a positive HCV test result being noted on 8th April 1999.

9. After being told that GRO-B had HCV by Dr McVerry, we asked him what would happen next and we were shocked at this response. He bluntly told us 'there's not a lot we can do' and seeing as GRO-B had 'obviously been living with it for such a long time', he didn't 'see it as a problem'. We asked him the worst-case scenario and he informed us that if it got really bad, GRO-B would need a liver transplant. At which I burst into tears. Moreover, GRO-B asked Dr McVerry if there was any possibility that he could have passed the infection on to me. He replied 'yes'. We then asked if I could be tested, to which he replied.... 'I suppose so'. He was very abrupt and unfriendly, constantly shrugging his shoulders and giving me the impression that GRO-B s appointment was now over and that I wasn't his problem. GRO-B was his patient not me. Dr McVerry was uncaring and very blunt. GRO-B then asked him if it was a blood disease or a liver disease to be informed that HCV was a liver disease. GRO-B told him in no uncertain terms that if that was the case, he wasn't happy to receive treatment from Dr McVerry and demanded to be referred to a liver specialist.

10. We were not given adequate information to help us understand and manage the infection by Dr McVerry. I am disgusted about the way both myself and my husband were informed of the positive HCV result. It was given without sympathy. The small amount of information we received from Dr McVerry was pitiful. Moreover, we only learnt that information because we asked questions. Dr McVerry said GRO-B had obviously lived and managed with the infection for at least 16 years. This astounded me at the time as to why, if GRO-B had been infected for so long, why hadn't he been informed before. Dr McVerry obviously knew the date of infection, to make the comment "16 years"

11. There was also a note (uncovered by Nurse GRO-B) stating a "weak positive" dated 10 January 1983. This may be the point at which he became infected with HCV.

Section 3. Other Infections

12. GRO-B received a letter dated 1st March 2005 from the Haemophilia Unit at St James Hospital regarding a possible infection of variant Creutzfeldt-Jakob Disease (vCJD) through blood products. We researched it and knew that they could not test for vCJD and we did not see the point of pursuing anything that would bring up bad memories for us.

Section 4. Consent

13. I believe that GRO-B was treated and tested without his knowledge and consent and without being given adequate and full information. I believe that he has been treated and tested for the purposes of research during the 16 years.

14. We were not informed that GRO-B had HCV until 1999. I believe that it was known by Dr McVerry that he was infected as far back as 10th January 1983. Since then treatments and tests have been undertaken by both Dr Swinburne and Dr McVerry knowing that GRO-B had been infected with HCV. I feel it has been one extreme cover up by The Haemophilia Depts, The Department of Health and the Government.

15. I refer once again to Exhibit WITN5650002 and note that GRO-B was tested for HIV (with a negative result) on 13th September 1985. Blood samples were taken at his annual routine appointments, but GRO-B was never informed that the samples were being used to test for HIV (and hepatitis).

Section 5. Impact of the Infection

16. GRO-B was stressed and worried beyond belief at the thought of how this infection might affect our lives. He was upset and felt that we had been let down by the treatment at St James Hospital. He couldn't sleep properly and suffered from

anxiety. GRO-B suffered with severe mood swings and hardly left the house unless absolutely necessary. We had to go through the stress of knowing GRO-B had the HCV infection from early 1999 until October 1999 waiting for a referral to Hepatology. Once he was under the care of the Hepatology Consultant we had to endure another 2 years of stress and uncertainty before his treatment eventually started in November 2001. It was explained at the time that they were waiting for the right treatment to become available.

17 GRO-B was eventually treated at St James Hospital under the care of Consultant of Hepatology, Dr C E Millson, and his Research Fellow Dr P Southern whom we saw several times between 8th October 1999 (the date of his first appointment) and 2003. He was treated with Interferon injections and Ribavirin tablets between November 2001 and June 2002. The treatment made him very ill, with severe side effects. He lost several stones in weight. He could barely walk some days. He had no energy and could not eat. He lost all interest in everything and couldn't work, obviously. GRO-B was that ill the Consultant had to lower the dosage on several occasions, and then gradually reinstate them. Towards the end of his treatment he was that ill he thought he was dying. He asked the consultant if he could finish the treatment early as he was so ill. The Consultant told him of the risks involved but agreed it was probably best to cease with the medication. I have never seen GRO-B in such a state of weakness, confusion and depression. GRO-B actually said to me that if he was going to die, there was nothing he could do about it, and said he just couldn't take any more of the side effects of the treatment. Over the next few months, he gradually got his strength back. Eventually we got the news that it appeared the treatment had been successful although he had to have regular check-ups and blood tests over the following 12 months before they could actually confirm that the infection had gone completely.

18 GRO-B was required to return on a regular basis for further blood tests to ensure that the HCV infection had not returned. This continued for a number of years

causing added anxiety and stress. Although he was given the all clear in 2003, even to this day, he still feels the effects of this traumatic time. The fact is that going over all this info regarding the HCV infection has brought back memories of a period of time he thought he'd locked away. He has found it very stressful and depressing although GRO-B knows he was very lucky to have survived it. We will be forever grateful for the care and treatment of the staff and doctors at the Hepatology Dept of St James' Hospital.

19. GRO-B at the present time is clear of the HCV infection, but he has been left with various health issues through being infected for so long. GRO-B has suffered for years with chronic IBS which we attribute to the HCV infection (which has ceased since treatment for HCV). In recent years he suffers from severe gum disease which we also attribute to the HCV infection. It is a known side effect of having had HCV.

20. Speaking for myself, when we first got the news that GRO-B was infected with HCV, I felt like I'd been hit by a train. My world was turned upside down in an instant when Dr McVerry said that the worst case scenario was that GRO-B may need a liver transplant and that he could have also infected me with HCV. Dr McVerry was so matter of fact and blunt. He had just informed us that GRO-B may die and that I myself could be also infected (and also die). That is exactly how I felt at that moment. My eyes filled with tears and I was crying. I remember that moment to this day very vividly. It still upsets me when I recall it.

21. Over the weeks and months that followed we scoured the internet for any relevant information on HCV that might help us get through this awful time. We got no information or counselling from St James Hospital or anywhere else. We didn't know where to turn or if there was any help available. We only had each other. Over the following months we did inform some close family members of our situation, but they found it all so hard to take in and understand, and also didn't know what to do. So, we stopped telling people. It was too hard

emotionally and psychologically to keep going over and over the details not to mention the Stigma attached at that time. One family member asked if she could catch it off [redacted] from being in the same room as him (I have never mentioned this to [redacted] until recently and [redacted] was devastated). Our life as we knew it had changed dramatically. I became very anxious causing me sleepless nights which made things even worse as I was already coping with having severe Epilepsy (Tonic Clonic) which I've battled with since I was 12 years old. Lack of sleep and anxiety are triggers for seizures. My Epilepsy was not in any way under control at this time. I was undergoing a trial experimental drug treatment as any of the usual current drugs had ceased working for me. This news couldn't have come at a worse time. I think a great number of the seizures over the next few years were definitely attributed to the stress and anxiety etc I suffered because of [redacted]s HCV diagnosis. I would burst into tears at the drop of a hat although I tried to keep a smile on my face for [redacted]. We would often end up crying in each other's arms. I lost weight and people would ask me if I was ill. I suffered from severe mood swings.

Impact Synopsis 1999 - 2003

22. During the period early 1999 to [redacted] getting his first all clear result in 2003, he was not the same person. Our relationship was very strong, as we only had each other. However, he felt we could not have any "close" relations, as he was afraid of passing on the infection to me. This prayed on his mind, along with caring for me. He was depressed. We were alone with this virus, with nobody to help us. The Hepatology Clinic (Liver Clinic) was marvellous as far as we were concerned. Our world was crumbling around us, not knowing what tomorrow would bring, but we had to get on with life. We suffered physically, mentally and financially. While he wasn't working, [redacted] would just tell people he was unemployed rather than explain the real reasons he wasn't working.

23. In 1999, I had 1st and 3rd degree burns on my legs due to a severe seizure. This took a toll on both of us. I was in and out of hospital for treatment, skin grafts etc. The nurse would visit the house and change my dressings. In 2000 I was hospitalised yet again after suffering severe back pain for months which resulted in me having my Gallbladder removed. Whilst all this was going on, I was on several different trial drugs programmes for my epilepsy for which we had to travel to York to attend York Teaching Hospital several times a month.

24. In 2001 after none of the drugs were working, I was referred to Sheffield Hospital to have a Vagal Nerve Implant fitted to try and help reduce the severity and reduce my seizures. This was an extreme procedure and very painful to say the least. However, as always, GRO-B was my rock and always by my side. My late mother paid and took us both on holiday abroad in September 2001 as she felt we needed a break.

25. In November 2001 GRO-B started his HCV treatment. I now had to be the strong one which I found very hard. GRO-B only had one day out of seven when he was feeling in any way 'normal'. The treatment made him very ill. He was sick, nauseous, depressed and moody. He couldn't eat. He was so tired he couldn't walk anywhere. GRO-B lost all his muscle tone and looked awful. When he did eat something substantial it would only be on a Sunday or Monday.

26. It would take GRO-B up to 3 hours to inject himself. He was afraid of needles but wouldn't let anyone else do his injections. He would worry about it for days before. This was constant and he lost weight and was a shadow of his former self. I thought I was losing him. I thought he was going to die. He administered the injection on Wednesdays and then would be ill from the severe side effects until Sunday or Monday. Then he would start worrying and getting anxious because he knew he needed to inject himself on the following Wednesday. It was a vicious circle.

27. Although we got through it all eventually. The pain of remembering all these details, even today, is like an avalanche. I am thankful that I still have my wonderful husband, and feel so deeply sorry for those that have lost loved ones to this terrible disease.

Section 6. Treatment/care/support

28. Once GRO-B received an appointment for The Hepatology Dept, I thought things might get better only to find that we had to wait another two years before any treatment could commence. We had another two years of uncertainty and stress and sleepless nights to cope with, dark times indeed. GRO-B had to self-administer his Interferon jabs weekly. He has a phobia of needles and would sometimes sit with the needle in his hand for two to three hours trying to psych himself up to do it.

29 GRO-B was not only my partner but took care of me during and after seizures. During the time GRO-B was ill from side effects of treatment, he made himself even worse trying to look after me. It was an awful time for the both of us. During this time, we had no professional support or counselling. Before all this happened, and even though I suffered from Epilepsy, we had a good life and things were going well for us. All that changed down to infected blood products that the Government insisted were safe.

30. At the moment the Government has insisted that the Covid-19 vaccines are safe although there is doubt over the possibility of blood clots. We, at the moment, have not taken up our offers of the vaccines. We are now very wary of trusting the Government regarding Vaccines etc.

Section 7. Financial Assistance

31. We only found out about the fact that there was any financial assistance from any Trusts or Funds when we entered into the Blood Enquiry system. We have never received any financial support regarding GRO-B's infection with HCV. We didn't know we were entitled to any.

Section 8. Other Issues

32. GRO-B has recently applied for his medical records. They are deficient and do not even include any of the information (and batch numbers) Nurse GRO-B had to hand during GRO-B's telephone appointment on 7th October 2020. We are chasing Access to Health for a full set of records, having pointed out to them that they need to make direct contact with the Haemophilia Department to access the records there. Nurse GRO-B has informed GRO-B (on 22nd April) that she has only just received the application and there may be some delay before he receives them (due to Covid-19).

33. Over the period mid 1980's to early 1990's GRO-B had numerous flare ups of extreme itchiness and rashes. Some of the several flare ups were more extreme than others. He suffered greatly with these and was at one point convinced (late 80's) that he had Scabies. He convinced me that we should both go for treatment to a local Scabies Clinic where they 'scrub you down' and then 'cover you in lotion'. I found this very embarrassing as I myself had no symptoms but went with him so as to make him feel better. I thought if he had scabies, then so must I. GRO-B's itching and rash still persisted, and it was obvious we didn't have scabies. Over the months his symptoms subsided and eventually cleared up and GRO-B was happy again.

34. I refer to Exhibit WITN5650003, being copy letter we have noticed from GRO-B GP to a Specialist dated 10th July 1992. It mentions elevated liver function readings and the concern that GRO-B might have 'chronic hepatitis'. This was probably the last 'flare up' of the symptoms GRO-B was experiencing and obviously sought medical advice from his GP.

35. GRO-B now remembers this period. He was indeed suffering another severe period of itchiness and rash and went to see his doctor. His doctor arranged for him to have blood tests and told GRO-B that, dependent on the results, he may refer him to a Specialist. His symptoms once again cleared up and didn't return. GRO-B at the time saw no need to take further treatment or consultation. At no time was GRO-B informed by his GP or any health professional that he might have hepatitis. Therefore, he saw no reason to worry about what had caused his symptoms. He cannot remember receiving appointment letters. Although, as I say, his symptoms had cleared up and did not return.

Anonymity, disclosure and redaction

36. I am seeking anonymity and understand this Statement will be published for the purposes of the Infected Blood Inquiry.

Statement of Truth

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

Signed GRO-B ....

Dated 29/4/2021