

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0496001

Exhibits: WITN0496002-005

Dated: 7<sup>th</sup> December 2018

## INFECTED BLOOD INQUIRY

---

### FIRST WRITTEN STATEMENT OF

GRO-B

---

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2<sup>nd</sup> November 2018.

I, GRO-B, will say as follows: -

#### Section 1. Introduction

1. My name is GRO-B. My date of birth and address are known to the Inquiry. I am married with one child. I intend to speak about my Hepatitis C Infection. In particular, the nature of my illness, how the illness

# ANONYMOUS

affected me, the treatment received and the impact it had on me and my family.

## Section 2. How Infected

2. I was 9 years old in February 1990 when I was admitted as an emergency to Sunderland General Hospital via my GP. I recall I spent 5 days in Sunderland, however, the clinicians were unable to diagnose my illness.
3. I was transferred to the Royal Victoria Infirmary (RVI), in Newcastle and was seen by Dr Malcolm Coulthard. Within 24 hours I was diagnosed as having Henoch-Schonlein purpura disease where the capillaries become inflamed and damaged and can cause serious kidney problems.
4. Dr Coulthard had discussions with my parents about my illness and when he discussed possible treatments he told them about plasmapheresis. Dr Coulthard said that plasmapheresis was not widely used but that he was convinced that it was beneficial. He had used it before on other patients with success. Removing my plasma and replacing it with donor plasma reduced the number of white cells and gave my kidneys a chance to recover. Because of how dangerously ill I was, my parents agreed to the treatment. My parents cannot recall being warned at any time that there were risks of infection connected to the plasma that I would receive.
5. They were told however, of the risk that the treatment may not be a success and that the worst case scenario would be that I would lose my kidneys would fail and I would have to be on dialysis and be

## ANONYMOUS

placed on the waiting list for a kidney transplant. I then had 11 plasmapheresis sessions over 2 weeks.

6. The product I was given was Fresh Frozen Plasma (FFP) during the month of February 1990.

### Section 3. Other Infections

7. No.

### Section 4. Consent

8. As I have set out at paragraph 4, my parents were not warned of the risk of infection connected to me receiving plasma.
9. I have been treated for the purposes of research. In May 1999 until February 2000, 9 months, I took part in the NHS funded trial of Interferon and Ribavirin combination therapy. Unfortunately I was a non-responder.

### Section 5. Impact

10. During September 1995, at the age of 14, Dr Coulthard phoned my mother at home and informed her of my possible infection with Hepatitis C. My mother tells me that Dr Coulthard was very shocked and upset at having to relay this news. My mother was informed I had been identified via the look back programme. He made arrangements for us to attend the Royal Victoria Infirmary ('RVI') for blood tests. My mother sat me down and explained what had just been discussed on the telephone. I was confused and didn't really understand, how could there be something wrong with my blood. At this stage we were hoping that a mistake had been made and that the test would be

## ANONYMOUS

negative. We were once again phoned at home by Dr Coulthard, and received the news we least wanted to hear. It had been confirmed that I was infected with Hepatitis C Virus (HCV). Again my mother had to talk to me and try and explain what had happened. She didn't know much and that we had to wait to see the Doctors at the hospital and discuss this with them. I was shocked, angry and very upset that I had been given a disease whilst in the care of the hospital who are supposed to make you better, not infect you with something else. Arrangements were then made to see Dr Eastam at the RVI to talk about the virus and to be booked in for my first liver biopsy.

11. I was referred to Dr Eastam at the RVI for monitoring. At my first appointment, I was with my Mother and Father and we were told I would be monitored and have regular blood tests and liver biopsies. It was confirmed that I was HCV Genotype 4 and this was very difficult to treat. Dr Eastam told us that there was no treatment available at this time and they did not know what the future held. Dr Eastam said I could be a carrier of Hepatitis C and that it may not affect me or I could develop cirrhosis of the liver or possibly cancer. This could take anything from 15 to 20 years to affect me but he stated that there could be treatments available before that time.
12. He also talked about the risks of transmission and the precautions I had to take. He told me, for example, that I needed a separate area for my toothbrush and razor. I was told that I could pass on the infection through blood to blood contact, sexual intercourse and mother to baby (childbirth). I was also made aware that I should not drink alcohol.
13. I remember leaving the appointment with a fear of the unknown. The medical establishment did not seem to know enough about the disease at the time and I was left as a teenager not knowing what my

## ANONYMOUS

future held with respect to my health. I felt very scared that I had something in my body that the doctors knew so little about; they didn't know how to treat it or how ill it would make me.

14. When I found out I was HCV positive I was 14 years old. I started to rebel against my parents because I was angry and couldn't understand why this had happened to me. I had so many unanswered questions because the Doctors didn't know the answers to them.
15. I feel that my schooling suffered as a result of finding out that I was HVC positive. I could not concentrate and also thought 'what is the point' if I could die in my 20s. I know that sounds extreme but that's the way I thought when I was 15.
16. On 14<sup>th</sup> December 1995 at the RVI I had my first liver biopsy. I didn't know what to expect. Because I was young and frightened they decided to do it under general anaesthesia. When I woke I was distressed and in pain. For several days after I remember being very uncomfortable around my ribs where the procedure took place.
17. On 17<sup>th</sup> December 1997 at the RVI I went for my second liver biopsy. Again this was done under general anaesthesia. The letter my parents received which provided my test results said that my liver was inflamed but there was no evidence of scarring (WITN0496002).
18. In 1999 I had my third biopsy at the Freeman hospital. I was told that they would not do this under general anaesthesia. It would be a day case and the procedure would be done under local anaesthesia. The days leading up to the biopsy were unbearable. I worked myself up so much I couldn't sleep. The day I went into hospital the nurse gave me a tablet which made me sleep until it was time for me to have to procedure because I was so frightened. I lay on the bed and when the

## ANONYMOUS

local anaesthesia injection went into my side the pain that shot to my hip and shoulder was horrible. Once that kicked in I was ok, but remember I cried through the full procedure. Again, in the days after the biopsy my ribs were sore and uncomfortable.

19. That was my last biopsy as they now do ultra sound Doppler liver and portal system and abdomen ultra sound, which is much less invasive.
20. When I left school I started work in a Solicitor's Office as an Office Junior. I told my employers of my condition. It was hard to explain to them about it because I did not know what would happen myself. I told them I would have 6 monthly hospital appointments and time off for a liver biopsy every 2 years. I ended up having more time off as I started my first course of treatment, an NHS funded trial with Interferon and Ribavirin therapy in 1999, aged 18. My employers were ok, but this started people talking at work and before long I was the talk of the office. I then felt I had to tell more people than I wanted to, some were supportive and some gave me a wide berth from then on; I can only presume it was fear of the unknown. This made very sad and I felt like an outcast. People can be cruel. From then on I decided no one would ever know about my health unless it was totally necessary.
21. During my first course of treatment the medicine made me feel really unwell. I lost my appetite and suffered nausea which was so bad that I lost a lot of weight. I became anaemic and had flu like symptoms every day after the injection (headaches, muscle pains, sore throat, feverish) felt dizzy and had nose bleeds. My legs bruised at the injection sites. I developed thyroid problems which I was told in a letter were due to the Interferon treatment but this rectified itself when I finished the treatment (**WITN0496003**). I found out in 2000 that the treatment had been unsuccessful.

## ANONYMOUS

22. I went through my second and third course of treatment whilst working for a different firm of solicitors. My second course of treatment was the Combination Antiviral Treatment which I received in September 2006. This treatment caused Interferon induced hypothyroidism and I started to take daily Thyroxin. This time the hyperthyroidism did not rectify itself once the treatment ended and I was informed that I had "Interferon-related hyperthyroidism" in February 2007 (WITN0496004). My thyroid is permanently damaged. I was devastated. Now I have to take tablets every day for the rest of my life. I had very similar side effects as I had during the previous treatment; flu like symptoms, nausea, fatigue and skin irritation. I was told in 2007 that the treatment did not work.
23. My third course of treatment was the Pegasys Pegylated Interferon which I received in 2008. Once again I had exactly the same side effects as before. It was very hard to deal with and get through day to day living but all I kept thinking about was how I could get rid of this disease and have a baby without having to worry about transmission.
24. I had some really difficult days during my treatments and felt that if people knew they might be a bit more understanding as to why I didn't feel like having a laugh with them or why I am a bit slower at my work today but I felt like I didn't want to be talked about again or shunned. This was a really difficult time. Mentally I was exhausted and physically drained.
25. My worries and fears during my treatment were: Will my career be affected by my illness? What if this treatment does not work again? When will there be other treatment available and will I be eligible to receive it? What if I develop any more long term side effects from the treatment? What is the chance of being infected with another disease via treatment received from the hospital?

## ANONYMOUS

26. When I was around 17 years old I had a terrible experience at a Dentist when I was registering with the Practice. I filled all the forms out in the waiting room and detailed all of my medical history as requested on the form. I handed the form back only for the details on it to be discussed very loudly by the receptionists and pointed at in a full waiting room. Everyone was looking at me. I was then told by the receptionist that I would not be able to be seen at that Practice because of my condition. I walked out of the Dentist in tears. They made me feel terrible like a second class citizen, like I was a walking disease. I never went back to a Dentist for 14 years after that experience. It was when I was pregnant that I registered with a Dentist. It was a totally different experience. He just thanked me for letting him know and was horrified when I told him of my last experience.
27. I went on holiday with a group of girls when I was 18. I was on treatment. I felt really unwell but I didn't want to miss out on our first girls' holiday abroad. The first problem occurred in the airport as I needed to go through customs with needles and a sharps box. Luckily, I had a letter from the hospital, in case I needed to ring them whilst abroad. The staff that scan your bags were fine once they saw this letter but having my bag opened and pulled to one side made me feel really uncomfortable. The second problem was when we were out on a night. We met some people and I was asked why I wasn't drinking alcohol. One comment was "What's the point of being on holiday if you don't drink".
28. Whilst on holiday I was fine during the day, sitting or lying around the pool. During the evenings however, I wasn't able to stay out with my friends. I was too exhausted. My friends took it in turns to come home



## ANONYMOUS

early with me. I was not able to dance the night away like any normal 18 year old would.

29. I started dating my now husband [GRO-B: H] when I was 17. [H] was my brother's friend so had always known I had been poorly from time to time. This made it easier for me to explain my condition, although I did fear that when he found out he might not want to put himself at risk. I dread to think how life would have been if I had to go dating to find a life partner and go through that awkward conversation about HCV and transmission etc. Once we had been together for a couple of years we had the discussion about children.
30. I was always told that there was a great risk of transmission with a sexual partner and from mother to baby. So with this information we made the decision together not to have children which broke my heart. From a young age I knew all I wanted was to be married and have two children.
31. In 2010 I got married to [H] having now had unsuccessful treatment 3 times. I felt that I had given it my best shot and knew there was nothing else to try as there were no new treatments available. After countless discussions we decided that we were going to try for a family. My desire for a baby was so great. I knew the risks and it was the hardest decision of my life.
32. We were blessed with a little girl in 2013 but not without complications. I had to have check-ups regularly because of my Thyroid (interferon induced Hypothyroidism). During my pregnancy I ended up having to increase my thyroxin tablets. At 39 weeks I went for a growth scan and was checked by a consultant. The consultant asked if I thought my waters had broken and I said I didn't think so. The consultant said that due to my HCV infection once my waters

## ANONYMOUS

broke the risk of infection increased as more time elapsed. I was admitted to hospital. [H] and I were shocked and he went straight home to get my bags.

33. After I saw the consultant I was then checked by a midwife, who was giving me the prostin pessary, she said she didn't think I was ready to be induced, but the consultant said to start me off. They broke my waters 17 hours after being admitted. 18 hours after my waters were broken I ended up having a C-Section. I believe all of this happened to me because of HCV.
34. One week after giving birth I felt something wasn't right with my C-section. I made several trips to my GP over the next 6 months and eventually my GP sent me for a scan. I had a C-Section hernia. An appointment for surgery was scheduled for a repair. After the operation I was not allowed to carry my baby for 4 weeks apart from when I was sitting down to nurse her. This was really hard for me and my baby.
35. I believe that if I didn't have HCV then I wouldn't have been started off in the first place which caused this entire knock on effect.
36. When my baby was 3 weeks old she was admitted to hospital. She was being sick and was generally unwell. She had bloods taken and when the results came back we were informed that she had elevated liver readings and was diagnosed with gastroenteritis. I just heard elevated liver readings. I broke down. I assumed I must have transmitted HCV to my daughter. The doctors said it might be because of the gastroenteritis but couldn't be sure. She could not be tested until she was a year old to see if she had contracted HCV.

## ANONYMOUS

37. For the first year of my little girl's life we had the horrible thoughts of "has she or hasn't she been infected with HCV?" My little girl was tested just after her first birthday and then we had the agonising wait to find out the results. Luckily she hadn't contracted HCV.
38. I then began my fourth and final treatment in 2016. For the first 4 weeks of the treatment I was irritable and couldn't sleep. I had sleep deprivation all the way through this treatment. My skin was itchy and drove me crazy at times. I got through the next 4 weeks just managing my skin irritation and sleep deprivation then week 9 hit me like a brick wall. I had no motivation or energy. My parents had to come and look after my little girl. I spent most of the last 3 weeks of the treatment in bed. I developed a chest infection which didn't help. This was really hard for me, seeing my 3 year old needing her mam when I was not able to care for her the way I should have been able to.
39. The only thing that was getting me through this was the fact that my body was responding to this new treatment. My viral load was coming down each time I had bloods taken. Thankfully and at long last I am now HCV undetected.
40. My diagnosis, illness and treatment has been so hard on my parents. They felt guilty for agreeing to treat me with plasmapheresis but if they didn't then my kidneys may have failed. They have faced a lot of turmoil about making that decision as well as suffering from anxiety and worry about how the virus would affect me in life.
41. When I rebelled as a teenager I know that it was very difficult for them. I had always been a well behaved child, then all of a sudden I stopped listening to them and started doing my own thing. They were worried I was going ruin my life and they felt my last years at school suffered. My brother, who is one year older than me, went to college

## ANONYMOUS

and then university and they thought this would be the road I would take.

42. I left school with poor exam results, after two years of misbehaving. This was a total shock to me and I think this is when I started to realise what I had done. My parents never knew how to handle this period in my life. They never wanted to be too hard on me because they knew what I was going through but at the same time they did not want me to ruin my future.
43. It was really difficult for them to watch me go through treatment after treatment. I remember a time during my first treatment when we were having Sunday lunch with my grandparents and I couldn't eat my food or even be at the table because of nausea. I went to bed while everyone finished, after that I could hear my mam in the back garden with my nanna, who was comforting my mam. My mam was crying because she felt so awful at seeing me so ill from the side effects.
44. It was always an anxious time for everyone when we were waiting for results to find out if the treatment had worked. My parents have always tried to be strong for me and have a positive outlook and pick me back up when I receive bad news.
45. When their granddaughter was born we all celebrated the birth but there was always the underlying fear of, what if she has been infected. They always worried and agonised over how they would be able to console me and their son in law if we ever got the news that our daughter had been infected. Thankfully this did not happen.
46. My husband has had to watch his wife suffer and his life was also put on hold as to making a family. We have had a child much later in life than we wanted to. After several years together he thought that he

## ANONYMOUS

could have HCV but because he was so afraid of needles he would not go and be tested. After all the failed attempts at treatment [H] decided that he would rather not know if he had HCV and just live with the consequences. He did not want to go through all the treatments which I had tried.

47. Once I found out that I was HCV undetected the realisation then hit him that now he may be the problem in that he may have HCV. This was a difficult time for him now having to know either way. [H] went for the blood test. He is petrified of needles so this was really traumatic for him. Then we had the agonising wait again for results. [H] was HCV negative.

48. We talked about and looked into immigrating to Australia then realised that we would possibly not be granted a VISA because I had HCV. We stopped looking into it because of the fear of rejection and disappointment that I have faced since contracting the disease.
49. My husband also had the opportunity of working in Qatar but because they screen for Hepatitis when entering the Country to work he never took this opportunity.

### Section 6. Treatment/Care/Support

50. In May 1999 I began 9 months of treatment with Interferon and Ribavirin ending in 2000. This was an NHS funded drug trial and I had to inject myself with Interferon 3 times a week and take daily Ribavirin tablets. I was not responsive to the treatment.
51. In September 2006 I began my second course of treatment which was a Combination Antiviral Treatment. This involved giving myself weekly Interferon injections and daily Ribavirin tablets. I finished the

## ANONYMOUS

treatment in March 2007 and found out that the treatment had not worked.

52. In January 2008 I began my third course of treatment which was the Pegasys pegylated Interferon. This involved a 180 mcg subcutaneous once weekly injection as well as Ribavirin (COPEGUS) 600mg BD tablets. Again the treatment did not work ( **WITN0496005** ).
53. In November 2016 I began my fourth and final course of treatment. This was a 12 week course of tablets which were 1:12 viekirax ABBVIE2D and Ribavirin. After this treatment I am now HCV undetected.

### Section 7. Financial Assistance

54. I regularly looked at the British Liver Trust web page and this was how I found out about the Skipton Fund. I felt that the form for the Skipton Fund and the form to confirm I developed an autoimmune disease was long and tedious. Having to recall dates, make arrangements to see my GP to get documentary evidence and also make appointments to see my Consultant/HCV Nurse to complete sections of the form was difficult.
55. I feel that once I registered with the Skipton Fund, however, I have always been kept informed as to any other financial support available to me.
56. In 2004 I received £20,000 from the Skipton fund. I can't remember which year I started to receive a winter fuel payment of £500 but it would have been after 2004. Then in 2016 I started to receive a yearly payment of £3,500.00 which included the winter fuel payment. From April 2017 my payment has been changed to a monthly payment of

## ANONYMOUS

£1,500.00. This is because I developed an Autoimmune Disease (hypothyroidism) whilst on treatment for HCV.

### Section 8. Other Issues

57. I have found it very hard to get life insurance. When I did find someone who was willing to insure me the monthly payments were too high and I couldn't afford them.

### **Statement of Truth**

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

Signed \_

GRO-B

Dated

12th December 2018