Witness Name: GRO-B
Statement No.: WITN1822001
Exhibits: WITN1822002-WITN1822003
Dated: 12 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1: Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry.

2. I live at home with my wife of nearly 16 years. I stopped work last year after having spent almost 20 years in the airline industry. I was a commercial manager. I had to stop work because of my health.

Section 2: How I was Infected

3. I was infected with Hepatitis C ("HCV") through a blood transfusion at Nottingham City Hospital. I do not know when exactly I became infected. I was there for treatment over a two year period from August 1989, when I was 18, to 1991. I was born with portal vein thrombosis, a condition which means that the vein between my liver and spleen is blocked, so blood has to find another way around my system. Varices grew in my oesophagus and I would suffer from torrential bleeding because the varices could not handle the pressure and volume of the blood going through them. I was constantly vomiting blood, pints at a time. At the worst point it would exit out of all orifices. I required regular blood transfusions over a period of about 2 years to treat this.

4. I think that during the time between 1989 and 1991 I received over 200 units of blood via transfusions from Nottingham City Hospital.

5. Before I embarked upon the treatment, I was told that I needed blood transfusions. I was lucid enough to understand that I needed this, but that was the extent of the discussion. I was not ever given any information or advice about the risk of being exposed to infection.

6. As far as I know, I was infected with HCV only.

7. I do not remember exactly when I found out I had been infected with HCV. It was some time between June and August 1995, and I was 23 years of age at the time. There is documentation in my medical records from January 1995 to February 1996 of correspondence between my GP and the hospital discussing testing me for HCV, my diagnosis and my prognosis going forward **(WITN1822002).**

8. I remember that came home from work and my mum was there. She told me that she had had a call from the GP surgery, who had told her I had HCV. The doctor had explained to my mum what it meant, and the little information she had, she gave to me. When my mum told me about my diagnosis, she was in tears. She thought that I had been given another death sentence, after living through my portal vein thrombosis.

9. I was glad that my mum told me, but I do not know why my GP did not tell me himself. I was not given adequate information to help me understand and manage the infection. My mum told me initially, and to my recollection I was not subsequently provided with any further information about it by any medical professional.

10. I believe the way in which I was told was diabolical; extremely unprofessional. I can understand why the GP spoke to my mum to give her a heads up and to ask her to bring me in. I had been going through a tough time at work, which my GP

knew about. I was the first person onsite at the GRO-B So it may be that my mum thought it would be best for the information about my diagnosis to come from her. However, there is a degree of professional responsibility which was totally ignored. It should have been down to me as to whether I chose to inform my mum and dad, as I may not have wanted to burden them with knowing about it.

11. I also consider that I should have been told of my diagnosis sooner and provided with information about it sooner. I think I should have been contacted personally by the relevant hospital doctor or clinician. The clinician should have called me in and explained it in full detail as soon as they knew. To come home from work one day and say "Hey Mum, what is for dinner?" and to be told, "By the way, you have HCV" was not the way to go. I believe that the doctors knew that the blood they were giving me could have been infected. In addition, I was having follow-up appointments every six months, which likely would have involved giving blood, so they would have or at least should have known sooner and I should have been told sooner.

12. I was never given any information about the risks of infection to others. I have researched that myself. I am very concerned about this because I have had nose bleeds, accidents and episodes of vomiting blood in the past, all of which could infect others around me. When an accident happens I have to warn people not to help me and I fear that they may become infected if they try to help.

Section 3: Other infections

13. I have been thoroughly checked and have only been infected with HCV.

Section 4: Consent

14. I do not remember a huge amount about what consent I was asked for before the treatment. However, I have to say that those that gave me the blood did so to save my life.

Section 5: Impact

15. When I was first told about my diagnosis, I was extremely upset to the point where I put my fist through a wooden door. I knew what the diagnosis meant; that HCV was the new AIDS. I had survived two years of being told that I would not live another hour (when I was having the treatment for the portal vein thrombosis). To survive that and have the expectation of enjoying life and carrying on with my life, to come home from work and have my life shattered again was too much. It felt like the end of the world to me.

16. I have been seeing a psychologist, Dr Shirley Grimshaw, to cope with the effects of my HCV infection on my mental health. She has provided a letter which explains some of the difficulties I experience. **(WITN1822003).** Dr Grimshaw states as follows with regard to the effect of finding out I had been infected:

> *The trauma of the original diagnosis cannot be underestimated. At the time when Mr GRO-B received the contaminated blood, he had been undergoing several very painful procedures and critical and complex surgery. But he had survived all of that, pretty much against the odds, and was in the process of putting those events behind him. Mr GRO-B then received the news that whilst receiving the many transfusions he had needed, he had been contaminated blood, the result of which was that he now had Hepatitis C virus. Having survived all that he had, the news devastated him. Had Mr GRO-B then received appropriate counselling for the trauma he had experienced, then those effects may have been lessened. But this did not happen and so Mr GRO-B still deals with the effects of that trauma in terms of flashbacks, anxiety and depression.*

17. The main impact of the HCV on me has been psychological. I know people who were told that the infection was not active and not to worry as a result but yet, the infection flared up some years later and resulted in liver failure. This concerns me. Dr Grimshaw explains this further as follows:

    a. *Mr GRO-B lives with the fact that Hepatitis C is a life-threatening virus. The uncertainty that that generates also has a direct effect on his level of anxiety and depression....also, each time Mr GRO-B is made aware of someone who, having been well for years, has suddenly become seriously ill from the virus and died even, it is a powerful reminder of the reality of the threat under which he lives. So* *intense has his anger and frustration been when those reminders occur that at times he has resorted to self-harm as a way of relief.*

18. I was recently - within the last couple of years - diagnosed with encephalopathy. Encephalopathy causes brain fog and alters your memory; I often lose my train of thought mid sentence. I think that it has been caused by the toxins that are within my blood. I am not sure if the encephalopathy was caused by the portal vein thrombosis that I was born with or the HCV. Other than the encephalopathy I have no physical symptoms of HCV at all. Prior to the encephalopathy diagnosis, the medics believed that the HCV was either laying dormant or had cleared my system.

19. I have had no treatment for the HCV specifically as I have had no symptoms.

20. For the encephalopathy I take 1000mg of Rifaximin twice daily. There is a huge difference in my health if I do not take it. If I do not take it, it feels like I am walking around in someone else's body and I do not really know what is going on. I do not know what the physical impact of the Rifaximin on my body is.

21. I have not faced difficulties or obstacles in accessing treatment. There are no treatments that I consider I ought to have been given, and I do not think having HCV has impacted on any treatment I have had.

22. In terms of the impact on my family and social life, the hardest thing for me has been not having children. My doctors told me that because I was HCV positive I could not have children as I would put them at risk of being infected. I am from a close family. I am very close to my mum and dad and my cousins. I always wanted a little girl to spoil. I grew up with three older sisters and I always used to babysit for my nieces because they were only six or seven years younger than me. I loved it and they loved spending time with me. They would have a blast, we would have a blast. I always wanted my own child to do that with. This was taken away from me and I am very upset and emotional about it; I do cry about it.

23. I feel guilt towards my parents for denying them grandchildren and denying them

the opportunity of seeing me have a family, but it is beyond my control. I would have loved to have had a son or daughter. Beyond that the worry and concern that they have had for me throughout their lives was huge especially to have the weight of HCV on their shoulders following the treatment for my original life threatening condition.

24. Having to tell my then girlfriend who is now my wife that I could not have children because I was HCV positive was dreadful. I did not know what she was going to do. It has had an enormous impact on our relationship. It makes me feel like a leper. In order to ensure my wife does not contract HCV, unprotected sex is not an open for us, which saddens me. I also have anxiety about the possibility of my wife becoming infected if our protection fails.

25. I tend not to tell anyone about having HCV because of the stigma associated with it. I had to tell my employer and as I moved from one department to another I would have to do this. One boss in particular was not particularly kind and even made a flippant, derogatory comment about drugs.

26. People have asked me directly whether I was infected through drug use. People have assumed that I am a drug user. I have had dirty looks on many occasions. At the dentist a few times, when I have had to fill out forms and included information that I am HCV positive, I can see the receptionists respond in a negative way. I am quite witted and usually deal with quite well but sometimes it leaves a mark.

27. I had to give up work because I was suffering from severe lethargy; the effects of the encephalopathy and severe gastro reflux. The gastro problems are related to the portal vein thrombosis but the encephalopathy I am not sure about. Obviously stopping work has impacted my life in a significant way, particularly financially. My income was close to £50,000 per annum. I have also had to pay for psychotherapy, which is not cheap.

28. I live in the UK, but I am originally from GRO-B in the United States and a lot of

my family still lives there. I am very close with them and would like to travel there often. However, I am unable to obtain affordable travel insurance because of having HCV. Therefore, I am only able to travel there without insurance, and only risk doing so for periods of less than one week at a time. I would love to visit for longer or even to return to live in the United States permanently. However, this is not a possibility because of the huge financial burden of healthcare and insurance in the United States. This makes me feel extremely upset and depressed.

29. I also worry about what would happen to my wife if I were to die from an HCV-related illness. Obtaining life insurance to support her through this possibility would be extremely difficult.

Section 6: Treatment/Care/Support

30. The only thing I want to say about this is that I have never been offered any support, nothing. The lack of support has been totally inadequate. Even now I would not know where to go. If I wanted a support group I would not know who I would go to, to ask. I am lucky to have an amazing gastroenterologist and hepatologist but I have only been under his care for the last 10 years and before then, there was nowhere for me to go. I relied upon myself to seek help and to seek support. It was always my mum and my dad and my wife. If it was not available to them then I should have been mailed in some way; perhaps from the mailing list that is held by the blood transfusion service or EIBSS.

31. I have sought help from a psychologist. One of my ex-work colleagues suffered from mental health problems in the past and recommended the person whom I now see. I especially needed to see this person when my mum passed away as I no longer had her support.

Section 7: Financial Assistance

32. I think I was told by a medical professional that I could possibly obtain financial

assistance. My gastroenterologist in particular was on top of everything, so I suspect I found out from him about the Skipton Fund in the mid to late 1990s. I then registered with Skipton Fund who kept me up to date.

33. I received £20,000 from Stage 1 of the Skipton Fund in the mid to late 1990s. I did not apply for Stage 2.

34. I received no financial assistance from then until around 2017, when I received £3,500 pro-rata from the Skipton Fund.

35. I started to receive payments from the England Infected Blood Support Scheme last year. I am in the Special Category Mechanism (SCM) and believe I receive £18,500 per year which is paid pro-rata.

36. Applying for the SCM was very stressful. My physical health, as a result of my other medical conditions had deteriorated to the point where I could not continue work. It put a lot of stress and worry on me when I applied because I thought I would get turned down flat as a result of past experiences of having no help and no support. It meant a huge amount to get into the SCM.

Section 8: Other Issues

37. I have fought for years to obtain recognition of the effects of being infected with HCV by contaminated blood. I lobbied my MP on this issue, as well as wrote to the House of Lords and worked with the Hepatitis C Trust as a campaigner to raise awareness of the infected blood scandal. I am now looking to start working directly with people infected by HCV to continue raising awareness of this issue.

38. This long fight has been stressful for me, as noted by Dr Grimshaw:

> *...what cannot be separated from the effects on his mental health of contracting the Hepatitis C virus, are the effects of the drawn-out fight that he has had to obtain recognition of those effects. He notes that compared with the compassion and support that is shown to others with life-threatening conditions, victims of contaminated blood have been treated*

> *with disregard. This has resulted in his feeling under-valued by those in a position to help, so that, while not suicidal, he has at times felt like giving up on life.*

39. I want recompense for what has happened. I want someone to apologise and I want those people who deliberately kept this quiet for so long, punished. I want to see people hung out to dry for this. I want the MPs responsible to go into a room; I want to see the perpetrators and I want a heart felt apology from them. I want changes to be made so that this cannot ever happen to someone else. If I took a syringe and withdrew blood from my arm and I went down to Westminster and waited for an MP to come past and injected my blood into them and told them I had been infected with HCV, I would be slung in prison. Their impunity cannot continue. They should expect the full weight of the law to come down on them. There are people who are dead today; needlessly, because this infected blood came into the system and on top of that, those responsible tried to hide it. They swept it under the carpet for decades and those responsible live high off the hog paid for by my tax pounds.

40. I really hope that we (the group of infected and affected individuals) will not be fobbed off again, but I have little hope that we will not.

Statement of Truth

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

Signature **GRO-B**

Dated ....12.02.2019..................