ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3110001
Exhibits: WITN3110002 – WITN3110007
Dated: 28 February 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I GRO-B will say as follows:-

Section 1: Introduction

1. My name is GRO-B. My date of birth is GRO-B 1946, and my address is GRO-B. I am married to my second wife, and I have no children and no other dependants. I am retired now but I used to work as a GRO-B, and later trained to become a GRO-B.

2. I am making this statement about the effect and impact of being treated with contaminated blood products.

Section 2: How Infected

3. I was diagnosed in 1980 with haemophilia B, also known as Christmas Disease. I suffered a haematoma after having some dental work and was tested for this condition when the blood loss was markedly significant. Blood was taken and it

was sent to St Thomas' for further testing. I received a letter from them dated 10 June 1980 which said I had mild Christmas Disease [WITN3110002].

4. There was a history of bleeding heavily in the family, but no one had ever been formally diagnosed with a bleeding disorder. I had no previous transfusions or treatment with blood products and was not treated at that time. In February 1983 I had a bleed into the left pre-patellar bursa and that time I was given Factor IX concentrate as treatment.

5. I was treated by Dr Gover at District General Hospital in Eastbourne ("District General"). I was not advised about any risks of being treated with this product, and I did not know much about those risks but was well aware what the blood product was and how it worked. The idea was that the product would supplement my own Factor IX levels and make my blood clot more quickly. I would have seen no reason to reject treatment with this product.

6. I had another problem with the same knee again in November 1993. At that time, they tested me for Hepatitis C and the test was positive. When I had treatment for the second knee problem, District General was already treating with synthetic Factor IX and so there was no risk of infection then. As such, the infected batch must have been the one that I was given in 1983 [WITN3110003]. I was given later treatments in 2002 and 2003 for the same problem in my knee and these would all have been with synthetic product.

7. I was not called into hospital specifically to be tested for this or any infection. I attended with the problem with my knee and I was asked if I had had a test for Hepatitis C before. I said I had not, so they tested me.

8. I cannot remember the advice I may have been given after receiving the positive test result. I believe I saw a Haematologist and I was referred back to my own GP. I do not recall being given any information about the risk of

transmission of this infection in November 1993. In 1994, I was given a lot more information at District General as part of a follow-up appointment I had with the Haematology Department. I attended haemophilia B status reviews every six months and I expect the haematology follow-up coincided with one of these.

9. I recall being tested for Hepatitis A in June 1994 and this was followed up with another test for Hepatitis C, which was positive again. The test for Hepatitis A was negative [WITN3110004]. A vaccination for Hepatitis B was also recommended which I had.

10. In 1994 I was also having liver function tests and these showed normal liver function at the time apart from a marginal increase of aspartate aminotransferase ("AST") levels. By December 1994, these had returned to normal again.

Treatment for Hepatitis C

11. Early in 1995 it was recommended that I begin Interferon therapy for the Hepatitis C infection, but I declined. I was told about the side effects of Interferon treatment, and how severe these could be, and hearing this put me off the treatment. I was reviewed again in October 1995 and, whilst I still had Hepatitis C, I was not concerned as my liver function tests remained normal and I had no outward symptoms of the infection. I knew that there were potential risks to avoiding treatment but it did not bother me at the time.

12. I had two more six month reviews after that, and was offered a hepatic portal vein liver biopsy to check liver status. I felt that there was too high a risk of haemorrhage and declined but, as I had started experiencing increased tiredness etc., I then agreed to have treatment for Hepatitis C in 1997. Eastbourne District General sent a letter to me dated 9 September 1997 about self-treatment with Interferon [WITN3110005], and this began on 29 September 1997.

13. The Interferon treatment was difficult. I felt tired and nauseous after each treatment. I was working with GRO-B at the time and needed help with difficult procedures. I had to get other GRO-B to help me because I could not cope on my own.

14. At the time, I can remember that the effects of the treatment were extreme fatigue, weakness, nausea, and at times an inability to think clearly. Most of my work was still do-able, it was just that I needed help with heavy shifts. I had no mental health concerns and, fortunately, I was cleared of the infection after six months of treatment.

15. I had another Hepatitis C test in June 1998 and this was negative with liver function test results being normal. It was recommended that I carry on with the treatment for another six months to prevent any recurrence, and so I did the full year of treatment.

16. The treatment stopped in October 1998 and in December 1998 I tested positive again. I believe there was a hiccup with the testing procedure, in that there was a complication with PCR testing to confirm if the infection was still present, so I was advised to carry on with the treatment. I do not know if this was because there was a doubt about the accuracy of the Hepatitis C test and this was a "belt and braces" approach to a general concern, or perhaps something more serious. I was disappointed that the treatment did not seem to have worked, but I did not see the point of continuing with Interferon anymore as it was clearly not working.

17. I continued to be reviewed regularly, and my liver function tests showed occasional spikes and slightly elevated levels of AST. In the absence of clinical symptoms, no action was taken about this other than continuing regular tests.

18. My next treatment for Hepatitis C began in 1999. This was PEGylated Interferon treatment and Ribavirin. In January 2000 I suffered a significant haemolysis. About two weeks after beginning the treatment, my wife noticed that my eyes had turned bright yellow. I felt awful and became jaundiced. The side effects from the last treatment meant that I had already had reservations and this time I felt worse. I stopped the treatment. I could not work for a few days after that. As soon as the treatment stopped, I got over the jaundice symptoms.

19. I had another Hepatitis C test to check if the treatment had been working but it remained showing positive for infection. I continued to feel very tired but I also acknowledged that I was working very hard and getting older. In retrospect, I am not convinced that any significant symptoms came solely from the treatment for the Hepatitis C infection.

20. I am self employed as a GRO-B in solo practice, so the concern was that someone would have to pick up my work and I would not have any clients left to come back to. As such I kept working.

21. The haemolysis and compromised liver would have left long term effects in many people, but my liver had originally been in good condition and so I was okay. Within a week the jaundice had subsided and my LFT results were normal again.

22. I abandoned attempts to treat the Hepatitis C after that. The haematologist suggested seeing me periodically and keeping in mind new treatments and developments that could come up in the future. I was happy with this approach. The haematologist had told me from the start that the genotype of Hepatitis C that I had, Hepatitis C 1A, was the most difficult to treat. They had always been upfront with me about that.

23. In June 2000 I had further dental work done and declined Factor IX cover. It could not be guaranteed that I would not be infected by a further unknown virus. That was also around the time that variant Creutzfeldt-Jakob disease ("vCJD") was in the general public awareness. I was instructed to take tranexamic acid to deal with potential bleeding.

24. Not long after that dental work, I was kicked in the head by a horse. I telephoned Eastbourne District General hospital to ask for treatment and they said they would be able to treat me with Factor IX. When I went in there was no record of my call and they could not access my medical records. They refused to treat me without seeing these. Three hours later it was discovered that they had no Factor IX at the hospital and had to collect it from Hastings. I was not treated until about six hours after the injury, although I do recall the doctor saying that there was "no permanent damage". I am still not sure if he meant damage from the lack of quick Factor IX treatment, or damage from being kicked by the horse!

25. I continued to put up with Hepatitis C symptoms, the tiredness in particular continued, but again I think this could have been from any other reason referred to above. This was until I was offered further treatment for Hepatitis C in 2018. I do not think I could have been offered this any sooner, as I believe this was when information became available to the medical profession about new treatment.

26. The treatment would be a new combination treatment, for which I could be placed on a waiting list. I had my first fibro scan on 25 February 2019 and a lower abdomen ultrasound scan on 1 March 2018, to determine if there was any damage in the liver. There was no significant fibrosis of the liver and the ultrasound scan showed no cause for concern whatsoever.

27. Doctors agreed that I was a strong candidate for treatment and there was some need for treatment to avoid infectivity. My wife did not want me to go through the Interferon treatment again because she had seen the effect it had had on me last time. She was not concerned about the Hepatitis C as it did not appear to be affecting me significantly.

28. I was offered a place on the waiting list for the new treatment following a review in April 2019. Dr Arthur Dunk, who had been my gastroenterologist at District General GRO-B. He had retired but returned as a consultant for some patients. At a further review on 17 October 2019 my liver function was normal and as the scans had also shown no abnormalities, I decided not to go ahead with further treatment. Although I still have the Hepatitis C virus it is not affecting me much now and I have decided to "let sleeping dogs lie" for the time being. Dr Dunk will review me every 6 months and start treatment if either of us think it necessary. I also have an annual review at the Haematology Department.

Section 3: Other Infections

29. In 1993, I was told that I was being tested for Hepatitis C. Doctors were aware of a general problem and tested for Hepatitis A first, which was negative. The Hepatitis C test was positive. I am not aware of having contracted any other infections through treatment with contaminated blood.

Section 4: Consent

30. I have given my consent to all medical tests that have been conducted me, and I do not believe that I have had any other tests or treatment without my knowledge.

Section 5: Impact

31. From 1999 to 2018 I was monitored every six months by a haematologist. I remember him telling me that if statins were required then this should be the low level and to keep an eye on my cholesterol level. I opted for Ezetimibe rather than statins to control cholesterol. Aside from that there were no significant problems.

32. I had a mitral heart valve prolapse ten years ago and because of this, a stress ECG is conducted every six months together with my liver function reviews. I have had no significant side effects as a result of this additional issue.

33. Had I been seriously affected by Hepatitis C I think I would have had further treatment. I am quite fit and still go on lengthy walking holidays. I would have been able to cope. Unfortunately, my medical records are not very illustrative but I do not think this is on purpose. It is simply the passage of time. The records I do have show positive results at present [WITN3110006].

34. I was tested for HIV in 1986 with a negative result however, I declined the vCJD test in September 2004 as it could affect my insurance and there was nothing they could do even if the test proved positive. I did receive a letter about it, but I did not see the point in responding to it, although I am aware that the offer remains open if I change my mind.

35. I have been lucky not to have faced any direct stigma as a result of the Hepatitis C infection. I have not told people about it unless necessary, for example, I have told doctors and dentists about so that they can take the usual precautions.

36. Overall, aside from the side effects of treatment which I have spoken about above, there has been little impact of this infection upon me. I am aware I have been incredibly lucky in that regard.

Section 6: Treatment/Care/Support

37. I had no difficulty in obtaining dental treatment as a result of the Hepatitis C infection diagnosis, however, I did have problems obtaining travel insurance. I had to shop around quite a bit. I had a permanent health policy at the time but I had to be off work for quite a long period before this kicked in. I did tell the insurance provider about the Hepatitis C diagnosis but I do not know if it affected the premium.

38. I have no complaint of the medical profession and their treatment of me. I do appreciate that there was an element of a "postcode lottery" as to what treatment people received throughout this episode. I was lucky enough to be treated by good doctors at a good hospital. I do have some sympathy with them as they had very little knowledge about what they were dealing with.

39. I have had no specific offer of counselling at any time, having said that, I am an adult in a medical profession and I suppose my doctors thought I was doing okay. I did not feel deprived of support at any time. I feel I was in control of the infection and its management throughout.

Section 7: Financial Assistance

40. I applied to the Skipton Fund in July 2004. Dr Gover at District General Hospital Eastbourne did help me fill in the forms. I received payment in September 2004 and had no significant issues in my application being processed [WITN3110007]. I found out about the Skipton Fund from the Eastbourne Haemophilia Centre. I have received no other financial assistance.

41. I did lose some work because of the help I needed with my practice during my treatment. My lost work was no more than £5,000 and I have suffered no other significant financial impact as a result of this treatment.

Section 8: Other Information

42. I feel I have got off lightly, and I appreciate that many have not. It is unlikely that I will have any long term effects of this infection and none have manifested yet. From a professional point of view, I suspect that some people who think they have ME may actually have Hepatitis C, they just had not been tested. My experience of the symptoms is that they are similar in both conditions.

43. What I seek from the Inquiry is for them to establish how this happened. We need to see evidence of when screening of the blood products was undertaken and what was found. I appreciate that not a lot was known by the medical profession at the time that this contamination happened, however, there does need to be some examination of who knew what when these products were being manufactured and sent to the UK for distribution to patients here. In November 1995 I did ask my then MP, Nigel Waterson, to sign an Early Day Motion calling for compensation for recipients of contaminated blood. I received a curt reply to the effect that he never signed EDMs as they were a waste of parliamentary time.

Statement of Truth

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

Signed: ....**GRO-B**...

Dated: 28th February 2020