ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN0115001
Exhibits: WITN0115002 – WITN011504
Dated: 28th May 2021

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 1961 and my address is GRO-B. I live with my wife who I have been married to since GRO-B.

Section 2: How infected

Haemophilia

2. I have Haemophilia A which is categorised as moderate to mild. This is because my Factor VIII level seems to have increased over the years.

3. I was diagnosed with haemophilia when I was around seven years old after I had suffered from a number of unexplained bleeding episodes over a number years. I was treated at St Mary's Hospital in Portsmouth from the age of seven until I went to university at the age of 18.

4. I am aware that I was originally treated with Cryoprecipitate which would have been in the late 1960s after my diagnosis and that I later transitioned to Factor VIII. I do not know exactly when that transition happened but it would have been around the mid-1970s. I do recall that I used to have whatever blood products were available at the time so I might have received Cryoprecipitate and Factor VIII during the same period. My GP medical records confirm that my clinicians at St Mary's Hospital were Dr J Moseley and Dr J O'Brien. During this time, I sustained numerous injuries which required treatment. Portsmouth Hospitals NHS Trust have denied that there is any record of me being a patient within their Trust which is surprising given that I was treated there for 12 years and my GP medical records contain correspondence from them.

5. I do not believe that my parents were made aware of the risks of receiving blood products when I was attending St Mary's Hospital and I was certainly never told about the risks when I got to an age when I would have been able to appreciate and understand them myself.

6. I have been treated by a number of other hospitals during my lifetime, the details of which I set out below. I cannot recall ever being informed about the risks of the blood products which I was receiving by any of the hospitals that were treating me prior to the late 1980s. My knowledge of the risk changed when I was attending the Royal Free Hospital as it was suspected that HIV was being transmitted through blood products.

7. In 1974, I had a surgical procedure carried out at the John Radcliffe Hospital and I have received a copy of my medical records from them. Dr Rizza from the Oxford Haemophilia Centre was the clinician who liaised with the hospital in respect of the blood products that were required to cover the operation and wrote to my GP post-operatively to confirm that the surgery had gone ahead under the cover of A.H.G. and Cyclokapron.

8. In August 1984 whilst I was on holiday in Cornwall, I had a very severe bleed from an injury which I had sustained prior to going on holiday and I was treated at the Treliske Hospital in Cornwall for ten days. I received a lot of Factor VIII whilst I was there and this would have been around the time that the risk of HIV

was becoming apparent. I recall that I felt like I was playing Russian roulette with my life when I received any blood products during this risky period. The injury (femoral nerve compression) caused me to have paralysis in my left leg and hip and it took me several years to recover and be rehabilitated. Unfortunately there are no records of my treatment and stay at Treliske.

9. In October 1984, after I secured my first job in Hertfordshire (I secured my job in September 1982), I had a car accident and I was treated at GRO-B GRO-B with Factor VIII but this is the only time that I was treated there. After this, my care was transferred to the Royal Free Hospital and I remained registered with them until 1990. My clinicians were Professor Lee, Professor Tuddenham and Dr Eleanor Goldman. I did not see Professor Lee or Professor Tuddenham very often at all and I was mainly attended to by Dr Goldman. I cannot recall if I received any treatment with blood products when I was registered at the Royal Free Hospital and unfortunately they do not hold any records of my time under their care.

10. I did go to work in Switzerland and Holland whilst I was registered at the Royal Free Hospital but I never received any treatment outside of the United Kingdom.

11. When I returned to the United Kingdom, I moved back to GRO-B and my care was transferred from the Royal Free Hospital to Southampton General Hospital and I have been registered at Southampton ever since. My clinician is Dr Kazmi. I am quite fortunate because during my time with Southampton General Hospital, I have only had relatively few instances when I have required treatment. I did request my medical records from Southampton General Hospital in September 2019 but did not receive a response to my request. I have since enquired about this with Southampton General Hospital and they have confirmed that they hold records for me from 1991.

Diagnosis with Hepatitis

12. I can establish, from the small amount of medical records which I have received, that in August 1978 (when I was still under the care of St Mary's Hospital) I injured my arm and had a bleed for which I received treatment. Not long after

that I became ill and I went to see my GP. I had jaundice, nausea and I was generally unwell. The handwritten GP record states that it was suspected that I had mild Hepatitis (it does not say what type) **[WITN0115002]**. I recall that we made the connection between the treatment I had received earlier in the month and the symptoms which I presenting with and that it was likely that my illness was due to Hepatitis but no further investigations were carried out. I was told to go home, rest and to go back in a few days if I was not getting better.

13. In relation to a formal diagnosis of Hepatitis C, I received a letter on 9 July 1990 (although the test was carried out on 29 March 1990) from Professor Lee of the Royal Free Hospital with the results of a blood test which said that I was positive for the virus **[WITN0115003]**. The letter said that they did not know what the consequences of this would be but that I could go on to develop liver disease later on in life. At the end of the letter is does say that Professor Lee would be pleased to discuss any of the issues with me at my next review or sooner but I do not recall having a review with her. It appears that the hospital was placing the onus on me to follow it up rather than them taking responsibility for it, especially as it appears to have taken nearly four months to contact me with this serious news. I was transferring from the Royal Free Hospital at around this time and it may be that I slipped through the net in terms of having a review, I do not know for certain.

Section 3: Other infections

14. I received two letters in relation to vCJD, one from the Royal Free Hospital and one from Southampton General Hospital informing me that I had not been treated with blood products contaminated with vCJD so as far as I am aware, I have not contracted or been exposed to any other infections.

Section 4: Consent

15. In the mid to late 1980s the Royal Free Hospital did test me for HIV and I recall that I was aware that they were testing me for it. I did not have the test for HIV frequently but certainly whenever I had an appointment (which was perhaps

twice a year from memory). I never received a call to let me know what the result was and was instead told that I would be contacted within a short period if the result had come back positive. This meant that the first day or so after a test, I would be worrying about the result. If 24 hours had passed, I would assume that I had tested negative and then I would just carry on until the next test. HIV was a major concern at the time and my girlfriend (now my wife) was invited to go and have a chat with the hospital about it. The hospital provided information to my wife about how to minimise the risks of contracting HIV because my understanding was that the test at that time was not fool proof.

16. When I tested positive for Hepatitis C in 1990, I only recall having routine blood tests as part of my annual reviews but I do not recall being told what they were being used for.

17. I did consent to participate in a Hepatitis study in 1998 at Southampton General Hospital and I received a letter dated 18 March 1998 from Dr Morag Chisholm, the Consultant Haematologist, informing me that whilst I had got antibodies for Hepatitis C, there was no evidence of the active virus in my blood which meant that at some point, I had been in contact with the virus but I had naturally cleared it **[WITN0115004]**.

Section 5: Impact

Physical/mental impact of Hepatitis C

18. As I have previously mentioned, I did suffer with various symptoms in 1978 when the GP informed me that he thought I had mild Hepatitis but apart from that, I do not recall having any other physical symptoms. I did have incidents of fatigue but I do not know if these were caused by Hepatitis C. There was nothing that made me think that I needed to go to see the GP.

19. Being diagnosed with Hepatitis C did have an impact on my mental health. Until I was told that I had cleared Hepatitis C, I did not know what the long term impact of it would be, would I develop liver damage? This was a worrying time

for me and it did cause anxiety. It still causes me some concern now. It is not something I think about every day but occasionally it does enter my thoughts. I also worry about what else I could potentially be infected with now and in the future and due to this, and what happened during the 1970s, 80s and 90s, whenever I sustained an injury, I would make my own assessment about whether it was worth the risk of receiving treatment. I have been told off a number of times by my Haemophilia Care Centre about this. In fact, when I was admitted to Treliske Hospital in Cornwall, I believe that this was the result of me neglecting an injury which I went on holiday with. It just got worse and worse and that is how I ended up in hospital for ten days and off work for six weeks. I should have had treatment when I sustained the injury but instead I dithered and delayed because of my reluctance to receive blood products. I know there are alternative treatments now and if I sustain a minor injury, I treat myself with DDAVP but that does not work for a large proportion of injuries.

Treatment for Hepatitis C

20. I was diagnosed with Hepatitis C in 1990 and I found out that I had cleared the virus in 1998 but during that eight year period, I was having regular check-ups, blood tests and liver function tests and I was not offered any treatment.

How infected status has impacted on medical treatment and/or dental care

21. I disclosed to my dentist that I have haemophilia and that I have been exposed to Hepatitis C. I was informed that the dentist would need to take additional precautions. Since this disclosure, I have had a number of dental procedures, one was done by the dentist but in other instances I have been referred to the hospital but I have not experienced any difficulties in obtaining dental treatment. I have had a few minor surgical procedures too but with the assistance of the Haemophilia Care Centre at Southampton General Hospital, I have not faced any obstacles in relation to them being carried out.

Family life

22. Due to the outbreak of HIV in the mid-1980s, my wife and I delayed trying for a family. Once we had overcome that hurdle, I was then hit with the diagnosis of Hepatitis C. By the time I had cleared Hepatitis C, we were faced with other issues and we sadly did not have a family.

Stigma

23. My brother (who is also a haemophiliac) and I went to State school. The school did not know how to deal with haemophiliacs and we were told by the school not to tell anyone about our condition because we would get bullied. There was a culture of secrecy in relation to haemophilia in any event without taking into consideration the problems which unfolded due to contaminated blood products. This has caused anxiety throughout our lives.

24. I declared my haemophilia to my employers but none of my colleagues knew and I did not tell my employers that I had been diagnosed with Hepatitis C. You never knew what reaction you would get. It was self-preservation, particularly in the 1980s when HIV became associated with haemophiliacs.

Work, financial impact

25. Being diagnosed with Hepatitis C did not impact on my work or on me financially.

Section 6: Treatment, care, support

26. I have never been offered or received counselling or any other support in relation to my Hepatitis C diagnosis.

Section 7: Financial assistance

27. I have never applied to any of the Trusts or Funds set up to distribute payments. It has only been in the last few years that I have found out that there is funding available to individuals who have been infected with Hepatitis C through contaminated blood. I have never considered that I would be eligible for it in any event as I cleared the virus without any treatment. I am currently considering applying to the England Infected Blood Support Scheme.

Section 8: Other

Medical records

28. I have requested a copy of my medical records from a number of my NHS providers. However, Portsmouth Hospitals NHS Trust, Royal Cornwall Hospitals NHS Trust and the Royal Free London NHS Foundation Trust have stated that they do not hold any records for me.

Section 9: Conclusion

29. I hope that the Inquiry can uncover the truth about what happened and what was known about contaminated blood products at the time when they were being given to patients as part of their treatment, a treatment which was supposed to help them live their lives. It is inconceivable that the risks associated with treatments were not shared with patients, but this appears to be what has happened. How can there have been a basis for consent without this knowledge being passed to the patient? I would like the families of those individuals who have sadly died, or individuals who have been affected by their treatment to receive an unreserved apology and those culpable identified. There should also be recompense for those remaining even if it can only represent a small token of the price paid by those impacted.

30. I would be prepared to provide oral evidence to the Inquiry should I be asked to do so but I would like my evidence to be given anonymously.

Statement of Truth

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

Signed: GRO-B

Dated: 28/5/21