Witness Name: GRO-B

Statement No: WITN 3044001

Exhibits: N/A

Dated: 7 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:

1. I am a person with Severe Haemophilia A (less than 1%). I have not had the benefit of accessing my medical records in making this statement and I am still attempting to locate my records from Treloars College.

2. I have a degree in Mathematics from the University of Bath and a PhD in Statistics and now have a unique insight both as an infected person who was given batches of contaminated blood products but also the statistical analysis of the risk that I and others have been exposed to and how this could have potentially been avoided or significantly limited.

3. Between 2000-2004, I have given talks to many doctors, nurses, health professionals and patients about blood contamination and infected status. I have found that there was a lot of anger in the room from patients particularly about geographical location and a 'postcode' lottery. There was also anger about the potential for payments from the various Trusts set up for compensation and the perceived unfairness of the schemes. This has given me a significant understanding of the issues faced and I have taken a lot from this work that was completed on a voluntary basis.

Haemophilia A

4. There does not appear to be a family history of Haemophilia although my mother (now deceased) did have a blood test. I am not aware of the results.

5. I was born on GRO-B 1968 in Wales and was prone to severe bruising as a child. I understand that the equivalent of child protection services did make some enquiries because of this. I broke my leg aged 3 and was treated at GRO-B Hospital where a junior doctor picked up on the comment from my mother that I bruised easily. When the cast was removed, I suffered a large haematoma when undergoing physiotherapy and was diagnosed with Haemophilia A that was severe (less than 1%) and was transferred to Cardiff Royal Infirmary under the care of Professor Bloom. As a result of Factor VIII treatment for this haematoma, I developed a severe, high responding inhibitor

6. Between the ages of 3 and 11 I had many painful bleeds but due to the inhibitor, I do not recall being given treatment other than Factor VIII treatment for the haematoma when I was aged 3.

7. I did not manage to attend school very often due to the severity of my bleeds; between the ages of about 5 and 6, I went to school for about 3 days in one year and about 15 days the following year.

8. In approximately 1975 I recall a time where I was admitted to hospital and was given treatment that I understood to be experimental, possibly an early Factor VIII inhibitor bypassing agent, and believe it was referred to as 'Bird's' treatment in the form of injections. I could not walk at all after being given the treatment. The bleeds were of shorter duration but I literally could not pick up and put one foot in front of the other; I had to learn to walk again. My understanding was this was pioneering treatment and I was one of the few people in the world who had been given this. I was not given this treatment again due to the side effects.

Treloars College

9. I went to Treloars College just before the age of 11 commencing in September 1979. My parents were simple Welsh Valley people who held the medical standard and doctors in very high esteem and trusted their word. They never would have questioned their advice. They were very stoic.

10. I was a bright child and my parents had tried to get me into a school in Bristol, but this was deemed not suitable. Professor Bloom had conversations with my mother and Treloars appeared to be a solution. I boarded at Treloars from 1979 until 1987 when I left aged 18 years and 8 months. During my time at Treloars I was never consented for treatment and never signed any consent form.

11. This was the first real opportunity I had for a formal education. There was a 'can do' attitude there and this was transformational for me. There was a mindset that disabled people can do anything. However, neither I nor my parents were aware that the treatments being given were contaminated until I was informed that I and other pupils were infected.

12. I did not immediately commence treatment when I attended as it was noted that I had inhibitors. I was therefore enrolled in Factor VIII inhibitor bypass treatment. Following the success of these bypassing agents in treating my bleeds, I was recommended to have a course of immune tolerance where I was given doses of Factor VIII to trigger an inhibitor response that tails off. I was given 1,500 units three times per week for approximately 18 months of a product I believe to be manufactured by Armour. This significantly increased my risk of exposure. I still have inhibitors but the definition appears to have changed over time to a low level responding inhibitor.

13. During my time at Treloars I was given FEIBA, Factor VII Inhibitor Bypass Agent, Autoplex and Porcine Factor VIII. The pupils at Treloars were used, in my view, as guinea pigs. The 2 main doctors were Dr Tony Aronstam and Dr Mounir Wassef. Many other doctors rotated and one doctor who attended called Dr Dasani, was very shocked at the number of batches that were in use at Treloars. There appeared to be no attempt to limit any exposure to infected

blood products. I am now aware of the significant risk in the use of multiple batches. My impression is that there were issues in relation to costs.

14. The duration of my bleeds was comparatively much shorter because of the treatment but were still longer than many other pupils and significantly painful. I was still having bleeds every fortnight. Doctors appeared to very much err on the side of caution and pain relief was not well managed, I had many very painful nights. My recollection is that there were only 3 instances over 10 years where the controlled drugs book was used for pain relief despite the severity of the bleeds and intense pain.

15. During my time at Treloars pupils did die at times and there was an element of denial about this. There was no counselling and pupils were expected to just carry on.

HIV

16. I was informed that I was infected with HIV at the same time as one other pupil aged approximately 16. I was not aware that I was being tested. I think it was around 1985. I never spoke to my parents about this, I thought it was a death sentence and my mind has blocked out the conversation. I was in denial.

17. My understanding of AIDS was what I had read in newspapers and what was being said in public at the time. This was towards the middle of the 1980s. During my time there, others at Treloars were diagnosed. Some pupils refused any further treatment but many others of us had the attitude that we were already exposed and likely to die in any event so continued treatment. It was almost a defence mechanism not to take very much notice.

18. I took the attitude that life was short and I was trying to take a pragmatic view. I wanted to take what I could as I thought I was going to die, and it was likely to be sooner rather than later.

19. I wanted to go to University, and I did well graduating in 1991 with a BSc in Mathematics. With my mortality looming, I was offered a placement to train as

a government actuary during the 'Milk Round' prior to graduation but I did not take up the placement due to concerns about my HIV. I thought this was a waste of money as the training programme is very long usually taking between 5-10 years to become a fully certified actuary. As I knew I was going to die, I stayed in the confines of academia. This gave me a feeling of safety and flexibility and meant that I did not have to disclose my status to attend medical appointments etc. I was extremely fearful of anyone finding out about my infected status. Academia is very conducive to ill health facilitating flexible time that permitted me to attend appointments.

Hepatitis C

20. I stayed in academia for the next 10 years. In the year 2000, my liver function tests started to become problematic and by the early 2000s my LFT were getting towards cirrhosis. I was given Interferon with Ribavirin in a trial and I believe they were testing a third drug, possibly Amantadine, but this did not work for me and I did not clear the virus. I decided to travel as I believed that I would die and spent the next 9 months travelling around the world. I spent the money that I had doing this as it was pointless to make plans for the future. I wanted to try to make the most of the time I had left rather than sitting waiting to die.

21. I was then given Pegylated Interferon and Ribavirin and was fortunate that this did not have too many immediate side effects for me. I was biologically neutropenic but did not require platelets. I was given a second treatment regime for 8 months.

22. I cleared the Hepatitis C virus but was left with massive cholesterol problems and issues with my triglycerides that required treatment and I have been left with bone density problems.

23. The Hepatitis C infection had a severe impact on me. I was tired and unwell and that is when the depression started. I had a significant dip in mental function

which was devastating to me. It is not clear to me whether it was the disease, the medication or a mixture of both, but I have been generally unwell since.

The Present & Future

24. I was very fortunate to survive as many others I have known from my youth and met in the course of my treatments and talks given, have passed but my infected status has had a devasting impact on my life.

25. The severity of the Hepatitis C is still being felt. I am still tired and unwell and am dealing with depression. I have always had such mental agility and could calculate numbers rapidly and with ease. I found this very frightening. The thought that I would lose my mental faculties was very depressing and debilitating. I am still grappling with the effects.

26. My infected status impacted on my personal relationships and I was very scared to become emotionally and romantically involved and this somewhat blighted my life. I did not have my first relationship until I was 25 and this was very short-lived due to fear about my HIV status. I was very fortunate to have met my partner and subsequently get married.

27. However, the denial I experienced about what has happened to me has caught up with me in these later years and has impacted significantly on my life. I have required professional counselling over the past 2 years and received exemplary care from Dr Dasani and his successors at Cardiff Hospital.

28. My father is elderly and I have never been able to discuss my infected status with him.

29. I have realised that even with my infected status I managed to gain excellent qualifications and saw how much I could have achieved had I pursued my chosen career. There were significant lost opportunities for me both professionally and personally.

30. I was told that my prognosis was poor and that it was likely I would die very young due to my infected status. This completely dictated life choices I have made.

MacFarlane Trust

31. I did receive payments from the MacFarlane Trust- a stage 1 payment of £20,000 and a further payment that I cannot recall. I have also received 2 payments from the Skipton Trust of £20,000.

32. However, the MacFarlane Trust has been a huge source of anger and frustration for me. Indeed, after the diseases themselves, it has caused me more dark thoughts and mood dips than anything else.

33. For an organisation that was meant to help us, it delivered significant hinderance and heartbreak. For an organisation that was meant to reduce discrimination and help those who faced it daily (as a young, single man when it was formed) I encountered nothing but discrimination from them- from the initial tiered payments, through their evolution to a means tested benefit, their horrendously inappropriate letters, the condescending attitude of 'be a good boy, jump through the hoops and you'll get your money', through to the final ignominy of them having salted away a lot of money for a 'rainy' day; I hate to tell you, but it had been pouring for many of us for many years.

34. I, for one, downed a celebratory drink on the day I realised that I would have nothing more to do with them.

Statement of Truth:

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

Dated the 7TH day of MAY 2019

Signed: GRO-B

GRO-B