Witness Name: GRO-B
Statement No.: WITN0985001
Exhibits: nil
Dated: 4/12/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B
ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 September 2019.

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

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B 1974 and my address is known to the Inquiry. I live with my partner and my two children aged seventeen and twenty years old. I work full time at a local college. I intend to speak about how I was told that I may be at risk of Variant Creutzfeldt-Jakob Disease (vCJD) derived from a blood transfusion and that I could no longer donate blood. In particular, how this has affected me. I wish to remain anonymous.

Section 2: How Affected

2. In GRO-B 1998, I was twenty-four years old and I had a very traumatic labour whilst giving birth to my son at Colchester General Hospital. I had a post-partum haemorrhage, although the hospital did not tell me this at the time. I was informed years later by the medics during the time my daughter was born in 2002.

3. After the birth of my son, we were both very ill. His airways were not cleaned out properly after he was born and so, he was admitted into special care for a few weeks with a lung infection. I was also very poorly. I felt unwell as I had a significant incision during the birth and I had lost a lot of blood.

4. Shortly after the birth, the Consultant came to speak with me. I was told that I would feel how I was feeling for six months to two years, or I could have a blood transfusion and I would feel better within two months. I thought to myself that I did not want to feel like this anymore and especially since I had a new born son to take care of, so, I chose to have the blood transfusion. As it turned out, I still felt ill for the following six months with exhaustion and anaemia, and it took a lot of healing time to feel my normal self again.

5. In 1999, four to six months after the blood transfusion, I received a letter from the NHS. The letter stated that the blood I had been transfused with, may have been contaminated and I may be at risk of being infected with vCJD. I cannot find this letter at present, but it may have been from the hospital that I had the transfusion at. All I know for certain is that it was from the NHS. To my memory the letter also referred to the individual who had donated the blood, without naming them, saying that they may be at risk and that if this person was diagnosed with vCJD then I would be informed. There was no further detail on the letter such as a clinician to contact for information. I was

left very much 'in the air'.

6. At that moment, I remember feeling really scared and in shock. I was left thinking that they knew very little about this disease and all I felt able to do was to just shut it all out. I do not think that I had time to process and comprehend the information properly as I was a new mum and naturally had a lot going on.

7. At that time, I was not ready to deal or cope with it all. I knew a little about vCJD; that it was grim and nasty way to die. I also did my own research which did not really help my mental state.

8. I remember thinking that I needed to wait for a further letter to find out more information. However, the only other letter that I received offered no information or guidance as to the condition that I may have. The letter was from the National Health Blood Transfusion Service. It said that they no longer required my blood donor services, with no further explanation. I had been so proud of giving blood and I wanted to continue, but neither would I want to put anyone else at risk, so I just accepted it.

9. Around ten years ago, I experienced some symptoms that made me think that it could be vCJD such as blurred vision, tiredness and 'pins and needles'. I now believe that it could not have been vCJD as it has not killed me and I know that once the disease is obvious it doesn't take long to die. That is an indication of the way I was thinking; anything unusual physically and it made me wonder if it was the vCJD. It is very unnerving and is always hovering at the back of mind as a possibility.

10. On introductory meetings to new GPs, I have mentioned my risk of vCJD when requested but I have never been tested for it. I disclose in all clinical forms that I am at risk of vCJD, but no one ever questions it and I have not noticed clinicians taking any extra care. No one has ever asked me to clarify my risk further.

11. I now have access to my medical records online and my blood transfusion is mentioned on there, but the vCJD risk is not. I do not believe that these are complete records.

12. Also, my online medical records state that I had my blood transfusion on GRO-B 1998. However, I do not believe this to be accurate as this is the date that my son was born and I had the transfusion a few days after his birth.

13. I saw the Infected Blood Inquiry (IBI) mentioned on the news which is what prompted me to get in touch as I wanted to see if it was relatable to my situation.

14. Since I contacted the IBI, I have carried out my own online research on vCJD. Over the years I have not really done this as I could not see the point in torturing myself. However, since I received the letter in 1999, research has moved on and more is known about it, however there is still no cure and it is still a horrible way to die.

15. Through my recent research, I found out that prions, which seem to be the cause of vCJD can potentially be passed onto your children. This worries me a lot and had I known this information then I may not have had another child. It has also given me a huge dilemma as to whether to talk to my daughter about it; I do not want her to carry this risk and worry with her.

16. I have not been tested for vCJD as I thought it was not possible. Following this meeting, I will attend my doctors and see if it is now possible to be tested.

17. I have kept this information from those close to me and I have only very recently told my children, but I certainly do not want them to worry about me. I feel that it is not something that anyone else can

understand unless they have experienced something similar themselves.

18. The issue for me is that I cannot predict or plan for anything and there is nothing I can do about it. I have no information apart from what I can see on the internet; I just have to wait and see what happens.

Section 3: Consent

19. I consented to the blood transfusion on the advice of the Consultant, however I obviously did not and would not consent to being transfused with contaminated blood. I trusted that the NHS were looking after me.

Section 4: Impact

20. Although, the letter that I received was brief and could have been a standard letter, it has left a huge impact on me over the years. It felt very personal as it was addressed to me and so, I always believed it was about me and my specific donor. The letter basically made me feel like I would have to sit, wait and see what happened to me. I remember thinking that I would never know if I was safe from vCJD as I would only ever hear further if my donor died from it.

21. It has had a significant mental impact on me as it is always there in the back of my mind. I have had to keep it hidden away in order to get on with my life. It is like a ticking time bomb that may or may not go off, but nevertheless ever present and more so when I'm feeling unwell or different.

22. Since I have been in touch with the Inquiry, vCJD has been on my mind an awful lot and it has caused me a lot of mental stress. Even preparing to be interviewed and thinking about how it has affected me has brought it to my mind and makes me feel so anxious. I do not like having to confront it.

23. I have a long history in my family of being a blood donor; both of my parents have had at least fifty donor sessions. It is something that I was very proud of. I started when I was eighteen years old and I gave blood every six months. I wanted to help people and it felt good to give back to the community. However, I was prevented from doing this due to my apparently unknown risk of having vCJD. I have felt cheated, annoyed and frustrated by this.

Section 5: Treatment/Care/Support

24. I have received no treatment, care or support following the letter from the NHS in 1999.

25. I think that it is ridiculous for me to be sent the previously mentioned perfunctory letters with nothing to back up the information. At the time, I was very vulnerable as I was only young, had just had a baby and so, my health was not my priority or concern. The information would have been better to be delivered face to face and for things to be explained in more detail to me. It is such monumental information to give to someone. The letters had no information concerning whether I could be tested, symptoms to watch out for and crucially precautions against onward transmission to anyone, but most importantly, to my partner and children. I also would have liked to have known and explained to me what options I had.

26. I should have had the basis for the information that I was at risk of vCJD explained to me and so, going forward I could have levelled my panic with how high the risk was.

27. There must have been many people in my position being kept in limbo and it is disgusting. It would have helped if I had the support from other people in the same situation as me. If it was a standard letter then this could have been explained too.

Statement of Truth

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

Signed GRO-B

Dated 4/12/2019.