

ANONYMOUS

Witness Name: **GRO-B**
Statement No: WITN2440001
Exhibits: WITN2440002- WITN2440006
Dated: 24th April 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

1. Introduction

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

2. How Infected

1. I suffer with Von Willebrands Disease. My **GRO-B** and **GRO-B** also suffer with this blood disorder. I refer you to Exhibit WITN2440002. This is a copy of a letter from **GRO-B** of the Blood Coagulation Research Unit at Oxford to **GRO-B** of **GRO-B**. The letter shows that myself and many of my family members suffer with Von Willebrands. The letter also shows the severity of the condition in each family member. In the letter **GRO-B** makes several suggestions in terms of lifestyle choices the family should be taking to help control the symptoms of Von Willebrands.

ANONYMOUS

2. I am from [GRO-B], therefore care for my Von Willebrands has taken place within the [GRO-B] Health Board. I have received treatment for my Von Willebrands at [GRO-B] and [GRO-B] [GRO-B].
3. I would say my Von Willebrands began to deteriorate when I started secondary school. At that time, I was around 11 years old. If I fell over in the playground I would bleed heavily and was often admitted to hospital for the bleeds. It was around this time that I realised I was different. I suffered particularly badly with nose bleeds. I would say my Von Willebrands was classed as 'moderate'.
4. My medical records show that I received a combination of Cryoprecipitate and Factor VIII treatment. I refer you to Exhibit WITN2440003. This is a letter from Dr [GRO-B] to Dr [GRO-B], the letter sets out the treatment I was receiving for my Von Willebrands in the 1990s.
5. I mainly received treatment from Dr [GRO-B] at [GRO-B]. To begin with, I was given Cryoprecipitate treatment. I can recall quite vividly what it was like to receive Cryoprecipitate. It would be administered through a drip and I remember the sensation of it going through my veins. The Cryoprecipitate was always given to me by a nurse or doctor.
6. I wasn't aware that I had been potentially infected from the blood I had received until I was told at [GRO-B] Hospital in the 1990s.
7. It was around 15 years ago that I had an appointment at [GRO-B] with Nurse [GRO-B]. Nurse [GRO-B] was a haemophilia nurse at [GRO-B]. During the appointment she said Dr [GRO-B] wanted to have a word with me. Dr [GRO-B] was a Haematology Consultant at [GRO-B].
8. During the meeting Dr [GRO-B] told me that I may have vCJD. Dr [GRO-B] said that if I did have vCJD it would affect my mental capacity and I could die

ANONYMOUS

from it. Nurse [GRO-B] then said the only way they could test for vCJD was when I die.

9. I was shocked at the way I was told I may have vCJD. I was taken completely by surprise. I felt angry over the fact I thought I was going to die before I could be tested when it was medical professionals who had infected me. I would like to refer you to an Exhibit WITN2440004, this is a letter from Dr [GRO-B] to Dr [GRO-B] dated 24th August 2010. In the letter Dr [GRO-B] states that due to the fact I may have vCJD I am “considered to be a risk for public health purposes”.
10. From viewing my medical records, I have seen that a vCJD exposure assessment form was filled out on my behalf. The form is exhibited at WITN2440005. The form sets out the batches of Factor VIII I received that may have been contaminated with vCJD. I would like to add that I had no knowledge that this risk assessment was being carried out.
11. My doctor at my GP Surgery was also notified that I fell into the “at risk” category. He was informed by the haematology department at [GRO-B] [GRO-B]. I refer you to Exhibit WITN2440006. This is the letter that was sent to my GP Dr [GRO-B] from the haematology department. In the letter, the haematology department at [GRO-B] informs Dr [GRO-B] that I fall into the “at risk” category.

3. Other Infections

1. In terms of other infections, I have not been diagnosed with any other infections. However, I would say my condition has led me to become frustrated by my circumstances.

4. Consent

ANONYMOUS

1. I believe I was tested without my knowledge and my consent. I also do not believe I was given adequate information regarding my potential vCJD infection.
2. However, I do not believe I have been tested or treated for the purposes of research.
3. I am unable to provide further details of the medical complications or conditions that can arise from vCJD as I have not experienced any severe symptoms yet and have not received a confirmatory diagnosis.

5. Impact

1. There has been no significant impact on my social life as my infection has not affected me in any way physically. I have been told that my infection will likely cause health issues as I get older.
2. What's happened to me has impacted my mental health. I find the unknown the most worrying part and not knowing what the future holds. As I have said earlier in my statement the only way I will know if I have vCJD is when I die. It constantly weighs on my mind.
3. Last year I was involved in a road traffic accident. Following the accident, I needed surgery. I was referred to GRO-B. There I was told that my vCJD risk would not affect any future surgery I may need to have. Once the surgeon had received my medical records from GRO-B he decided not to go ahead with my operation. I believe he didn't want to go ahead with my operation due to the vCJD risk. The same surgeon then said he would perform the operation on the NHS but would not be performing the operation privately. I do not know what the surgeon's reasoning was for this. In all honesty, I don't understand why it was the surgeon's preference to perform this operation on the NHS. In the end I did have this operation at GRO-B in late 2019.

ANONYMOUS

4. My [GRO-B] knows that I am classed as a vCJD risk for public health purposes. My [GRO-B] is also aware that in future I could suffer from physical and mental problems as a result of my vCJD exposure.
5. When I was younger I missed a lot of school due to my Von Willebrands. Luckily, my working life has not suffered as a result of my Von Willebrands.
6. As I have stated earlier in my statement, a lot of my immediate family suffer with Von Willebrands. Both my [GRO-B] and [GRO-B] have been infected with contaminated blood. They have both been diagnosed with hepatitis C. They have been through hell and back. The mental strain they have suffered is beyond belief.

6. Treatment/Care/Support

1. I have not received any counselling or psychological support. As I stated earlier in my statement I have suffered from frustration and resentment as a result of what has happened to me.

7. Financial Assistance

1. I have not received any financial assistance and I have never thought to apply for financial assistance as I have always worked.
2. My [GRO-B] and [GRO-B] both receive monthly payments from WIBSS.

8. Other Issues

1. I would just like to know the truth about what happened. I think that this has been swept under the carpet and we need answers. I would like to know how they got away with it for long. All I want is accountability because no one deserved any of this.

Statement of Truth

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

Signed

GRO-B

Dated 24 / 04 / 2020