

Witness Name: GRO-B

Statement No: WITN2381001

Dated: 15 January 2019

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 12 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 and address are known to the Inquiry. I was born in GRO-B and live there now with my partner and daughter. I am technically the youngest of my family. I have an older brother GRO-B: B.
2. I was infected with hepatitis A, hepatitis B (HBV) and hepatitis C (HCV) from contaminated blood or blood products in the period in between 1980 and 1989.

2. How Infected

1. Both my brother and I have haemophilia. I understand that it is passed down from my mother's side of the family. Times were different when I was little so the condition wasn't something that we talked about with people outside of the family. I just knew that something was different about my childhood.
2. The type of haemophilia is known as haemophilia B also known as Christmas Disease. Christmas Disease is a form of haemophilia caused by a deficiency of the blood clotting factor IX rather than the more common factor VIII. Christmas disease can cause prolonged or spontaneous bleeding. The less factor IX your body produces, the worse your symptoms are.
3. I was a haemophiliac from birth. As my brother had haemophilia I was tested when I was born as the condition affects the males of the family.
4. My first major incident happened when I was around two years old. I had been playing on the floor in my house and must have fallen. The inside of my throat began to bleed. I was rushed to Cardiff University Hospital and required emergency surgery. The doctors performed a blood transfusion and administered factor IX blood product.
5. Following this incident I was in hospital for around two or three weeks. It took some time for the injury to stabilise before I was able to return home. I was then referred to the Cardiff Haemophilia Centre at the University Hospital of Wales, Heath Park, Cardiff CF14 4XW and placed under the care of Doctor GRO-B This incident was the beginning of a childhood dominated by constant trips to the hospital.
6. It was difficult as a young child having haemophilia as it puts restrictions on how you can play or socialise. I was always at risk of

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serious injury arising from the smallest bump or scrape. Looking back it would have been a really stressful time for my Mam, GRO-B and my Dad, GRO-B constantly worrying about me and my brother.

7. I got used to attending the Haemophilia Centre in Cardiff. Dr GRO-B managed my condition using Factor IX treatment (Benefix). I have had to ask my mother about the time when she was informed that I had been infected with hepatitis C. I was so young that my memory of it is very vague and I didn't really understand what was happening. My Mam believes that it was in 1989 when she was told that me and my brother had been infected.
8. It was at the Haemophilia Centre in Cardiff when Dr GRO-B asked my Mam to come into a room on her own without me and my brother. I understand that she was told by Dr GRO-B that my brother and I had contracted hepatitis C from the blood products that we had been using.
9. My brother's immune system fought the infection and cleared itself of HCV but mine did not.
10. A few months later, my brother and I were tested for HIV. A nurse from the haemophilia centre GRO-B came to our house to inform my Mam of the results of the HIV tests that had been carried out. Fortunately both of those tests came back negative.
11. My Mam will give her own evidence to the Inquiry which will provide more detail about what she was told and when. I know that she was unsure of what to do when she was informed about the infection. She was told to avoid sharing toothbrushes and razors in the household but she was never given any real information about how serious a condition hepatitis could be.

12. My Mam is certain that she was never warned that the blood and blood products given to me and my brother carried the risk of infection with any disease or virus.

13. I know that this was extremely difficult for Mam and she has told me about how worried she was and how little information and support she received. She also felt that the news about the infection was told to her in a very unprofessional and insensitive way.

3. **Other Infections**

1. In 1988 I tested positive for hepatitis B, in 1989 I tested positive for hepatitis C and in 1989 I tested positive for hepatitis A.
2. In 2001 I was informed that there was a potential risk of being infected with VCJD but I have never tested positive for this.

4. **Consent**

1. I was never told about any risks associated with the use of factor IX blood products.
2. I was certainly tested without my knowledge and consent. Neither myself, my Mam or my Dad were told before I was apparently tested for hepatitis A, B, and C.
3. I learned from my medical records that in 1988 I tested positive for hepatitis B, in 1989 I tested positive for hepatitis C and in 1989 I tested positive for hepatitis A. My Mam was only ever informed that I had contracted hepatitis C. This means that not only was I tested for hepatitis A and B in secret but we were never even told I had tested positive.

4. Looking back, I definitely felt like I was being experimented on. I don't know the purpose of these experiments but all I hope is that the experiments benefited haemophiliacs in the future and humankind in general so I can make some sense of what happened.

5. Impact

1. In terms of the physical effects of my infection with HBV and HVC, I was aware of the damage that could be caused to my liver and as a result I never drank or smoked which made my lifestyle different from my friends. I felt like I missed out on a lot of the normal activities I would have enjoyed as a young man growing up.
2. Having been unwell so frequently when I was younger, it is quite difficult for me to distinguish the symptoms of HBV and HCV and the effects of haemophilia. However, as I have grown up I have seen such dramatic improvements in haemophilia care that I feel that had I not been infected with HBV and HVC then I may have been living a relatively normal life by now.
3. Instead, I currently suffer from very high blood pressure and thyroid condition. My recent liver test has confirmed scarring on my liver and I have to be reassessed every six months now to check on my liver function.
4. The mental effects of my condition have been extremely severe. I have suffered with depression for most of my adult life. This was significantly worsened by the treatment I underwent for HVC called Interferon.
5. In addition, the Interferon treatment caused me to suffer Hyperthyroidism and Thyroiditis which I still struggle with now the treatment is over.

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6. I accept that my educational prospects were affected by my haemophilia as I was often out of school and in hospital. It was impossible for me to focus and concentrate whilst having treatment. However, my work prospects as an adult have been ruined by the infection with HBV and HVC. I am constantly unwell, fatigued and depressed which prevents me from being able to work. I feel that the infection has stopped me from getting where I wanted to in life.
7. I feel that I have been lucky to have such a loving family and they have supported me. As a family we have become used to a hospital environment. A huge part of my life has been travelling in and out of Cardiff for treatment. However, I know that all of this has been incredibly hard on Mam and she was constantly stressed out when I was younger. The infection with HBV and HVC meant that she hasn't had any rest even now I am an adult. Mam still lives next door to me now.
8. In 2001 I was informed by the Haemophilia Centre that there was another risk of infection with VCJD that people were being tested for. Fortunately this worry proved unfounded.
9. I know that Mam was very careful to keep private the fact that me and my brother were infected with HBV and HVC as she wanted to protect us from judgement. Only close family members were allowed to know. We all dreaded having to tell people about it. We would have to remind doctors about it and mention it at the dentist. It was especially difficult having to tell my partner GRO-B
10. In 1999 my partner GRO-B had to have a test for hepatitis as she was pregnant with my daughter. Thankfully the result was negative but it was a very troubling time for the family. My daughter GRO-B was also tested as a baby but she was also negative.

6. Treatment/Care/Support

1. I was offered a treatment for HCV with Alpha Interferon injections and Ribavirin in December 1997 through the Haemophilia Centre. The reason I decided to undergo the treatment was that I had been warned that hepatitis C could cause my liver to fail if it was left untreated. I remember that I was told that there could be some side-effects to the treatment but I had no idea how severe those side-effects could be.
2. The treatment with Interferon and Ribavirin was the worst I have ever felt in my life. It was extremely frightening and I did not know what was happening to my body. I was tired, all of my limbs were aching, my head was aching and I was in pain all day long.
3. The treatment made me so depressed, I remember from the moment I awoke in the morning until I went to sleep at night, I felt like I didn't want to live. Every day I wanted to take my own life, seeing what this was doing to me and my family.
4. After a very difficult year of treatment with Interferon injections and Ribavirin I was pleased to be tested negative for HCV in December 1998. At this point my liver function tested normal and I thought that this nightmare was over.
5. Then in April 1999 I was devastated to learn that I tested positive again for HCV and the condition had relapsed.
6. I was offered a further course of treatment in 2001. Initially I did not want to go through it again. However, the doctor promised me that the new treatment had a much better success rate and that I would be a fool not to take it. The second time I did the treatment, I did it for my family. I felt I needed to try harder then, especially for Mam and Dad. They were hit so hard by the news that I still had the infection – I felt that I owed it to them to try.

7. Once again I was extremely unwell from the side-effects of the treatment. I was in so much pain I could barely put my clothes on.
8. My parents are not aware of this but during the course of both of the times I had the treatment I attempted to end my own life because of the pain and mental torture, without even thinking about the implications and what I would have left behind. Sadly, this still keeps me awake at night and I wake up in sweats knowing that I would have done this. Some things you can't forget and this will stay with me always.
9. After the treatment I felt so alone and I needed help coping so I accepted psychological support and I was seen by a really good therapist [GRO-B]. During the treatment I had been offered an anti-anxiety medication and tranquiliser. I was worried that if I started taking these I would never come off them so I turned it down in favour of therapy. [GRO-B] really helped me to think about helping other people and not being spiteful or bitter about what it happened.

7. **Financial Assistance**

1. A few years after I finished my treatment [GRO-B] the social worker at the hospital, told me about the Skipton Fund. I filled in the application form and was initially awarded a stage one payment. I now receive monthly payments. I didn't face any obstacles in making that application or receiving my payment. However, it would have been better if I had been told about the scheme years ago when I was first diagnosed.

8. **Other Issues**

1. The most difficult thing to deal with having been infected with contaminated blood is the effect that it has on the family. My Mam put

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her trust in the doctors responsible for my care and she feels so let down.

2. I feel like the blood products I was given both saved my life and ruined it at the same time.

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Statement of Truth

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

Signed.....

GRO-B

Dated.....

15/1/19

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