

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN2832001

Exhibit No: WITN2832002

Dated: 8th May 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 18th March 2019. 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. I am writing this statement to record my experience of growing up with haemophilia A during the period of the infected blood crisis and of my experience of being exposed to the risk of infection via blood products. In addition, I will discuss the impact on my mother, GRO-B, and the

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effect on our family of the death of her brother and my uncle [GRO-B: U] [GRO-B: U] in [GRO-B] from contracting HIV from contaminated Factor VIII.

2.How Infected

1. I was born in [GRO-B] and was tested for haemophilia in [GRO-B] at [GRO-B] under Consultant Paediatrician [GRO-B] [GRO-B] who confirmed I had moderate haemophilia A. My mother knew she was a haemophilia carrier and we have an established family history going back to my great grandfather.
2. I was very young, probably about [GRO-B] years old in [GRO-B], when I became aware that my late uncle, [U], had become ill. I did not know about the nature of his illness due to my age and [U] died when I was [GRO-B] years old. As time went by my family talked about the nature of [U]'s death however, as I was so young, I couldn't really understand the nature of his illness or the implications it had in relation to my own future.
3. My hospital records indicate that I had my first Factor VIII (8Y) treatment at [GRO-B] in [GRO-B]. In [GRO-B] [GRO-B] Haematology Department, [GRO-B] Haematology Department and [GRO-B] Director of Finance indicate there was confusion regarding whose responsibility it was to fund and provide Factor VIII (high purity) for children living in [GRO-B] at that time. The problems were resolved by [GRO-B] and it appears from my case records that I started to receive Factor VIII 8SM by [GRO-B]. From this time I also had regular clinic appointments and home visits from [GRO-B]'s outreach service as well as being a patient at [GRO-B].
4. Throughout my childhood I would have treatment for bleeds mainly caused by injury. I do not recall suffering from spontaneous bleeds. I was encouraged to be active and would have prophylactic treatment when undertaking activities that required cover. As a young person I cannot recall ever being told that there could be a possible risk of infection prior to having any treatment. A letter in my hospital records dated [GRO-B] from [GRO-B]

[GRO-B], Consultant Paediatric Haematologist at [GRO-B] to [GRO-B] [GRO-B] and [GRO-B], Consultant Haematologists at [GRO-B], states that my mother requested that my [GRO-B] and I receive the high purity Factor VIII. Records do indicate that this treatment was funded. As an adult I currently use Recombinant Factor VIII.

5. Regarding matters surrounding information sharing I feel that, when my mother was being tested in the early [GRO-B] in order for her to consider whether to have children or not, information that may have been available regarding emerging viral risks was not shared with her at the time. This wasn't shared even when it was confirmed that she was a haemophilia carrier. Prior to her getting pregnant with me in [GRO-B] and my [GRO-B] she wasn't properly informed that, by having children with haemophilia, there was a risk of contracting hepatitis C or HIV from Factor VIII at that time. It seems it was down to luck that I was never exposed to contaminated Factor VIII. I did not have an injury or bleed that required treatment until I was [GRO-B] years old in [GRO-B]. I think this is mostly because my parents tried to ensure that both my younger brother and I avoided unnecessary risks growing up. Luckily my [GRO-B] who is [GRO-B] years younger than me and who also has haemophilia A, did not need to have any treatment until he was [GRO-B] years old in [GRO-B]. I do feel it has been down to luck that we were not infected by either HIV or hepatitis C.
6. I am now married and as a parent of [GRO-B] young children I now feel that I have a better understanding of the risks my [GRO-B] and I faced as young boys growing up. It was right at the height of the contaminated blood products scandal during the 1980's when the media was at its most alarming with Tombstone adverts and the press spreading fear of a plague. As a teenager, the risks of HIV or hepatitis C didn't really sink in. But now I think it is criminal that the information that was emerging in the early 1980's about the doubts and risks of Factor VIII were not fully explained or provided to my mother. She should have been better informed about the potentially life-threatening risks of having a haemophiliac child.

3.Other infections

1. When I was [GRO-B] I received a letter informing me that I had been exposed to a batch of Factor VIII products that had been contaminated with vCJD. I do not have a copy of the letter; however, I believe I received it around [GRO-B]. At that time, I was a student living independently at [GRO-B] University. To receive a letter through the post was scary and a great shock to both me and my family. This was the first time I had heard of the risk to haemophiliacs. The media had been full of horrific scare stories about 'mad cow disease'. To receive a letter with no support offered and no invitation to discuss being exposed was shocking and I think it was terrible to have been informed in this way.

2. The only other references I have had to my vCJD status has been through a letter dated [GRO-B] from [GRO-B] Consultant Haematologist at [GRO-B] [GRO-B] to [GRO-B], Consultant Haematologist at [GRO-B] when I moved back to [GRO-B], confirming 'He is at risk for vCJD for public health purposes'. Recently I have had to provide a letter [GRO-B] regarding me being classified as a 'patient at risk of vCJD from British Blood Products (1980-2001)'. The letter was from the [GRO-B] Haemophilia Centre to [GRO-B] Hospital, [GRO-B] as I had to have Factor VIII treatment prior to a minor surgical procedure.

3. I have never been offered any follow up information regarding the risk of vCJD of any kind. No one has since got back in touch with me to give information regarding any statistics of people who had been infected through blood products or whether I remain a risk or indeed whether there is any general risk remaining at all?

4.Consent

1. As far as I am aware, I have never been treated without mine or my parent's knowledge or consent. My mother is a Core Participant and has submitted a

more detailed statement outlining our family's story of my childhood experience of growing up with haemophilia through the 1980's and 1990's.

5.Impact

1. With regards to my [U] death in [GRO-B] I feel very upset that it appears that his death could have been prevented. He was a fantastic uncle, role model and a great support to my parents. I grew up at a time when there was a lot of negative media coverage of HIV and AIDS which resulted in me facing a difficult time as a teenager. I was wary about who I discussed my haemophilia with. An example is when studying for my GCSE Biology in [GRO-B] the teacher was talking about HIV, not realising I was in the class, and he went on to discuss that the people most at risk were drug users, homosexuals and haemophiliacs. There was a stigma as a teenager of associating haemophilia with all the other risk groups. I must point out I am not homophobic or unsympathetic to people with substance misuse issues but, as a teenager, it was a difficult time to process all the negative connotations during a time when you wanted to just get on with life and not be seen as 'different' to your peer group. It was enough coping with the issues I had to deal with just managing my treatment in order to fully engage with all the school and social activities that I wanted to be involved with at the time. There were negatives to growing up with haemophilia. I enjoyed sports and missed out on playing rugby. I played football when I was a teenager but had to give it up as the risk of injury and my recovery time increased. As an adult I am concerned that, as I get older, I am more likely to develop arthritis compared to others because of past injuries to my joints.
2. Regarding me having haemophilia I feel that my mother feels an underlying guilt which comes to light whenever my brother or I have a bleed or are in pain. I feel that my mother would have delayed having children had she been fully aware of the risks of contaminated treatment at the time. Alternatively, she may have taken the opportunity to have an amniocentesis test at the time. However, if our mother had chosen that pathway my brother and I would not be here now. She took a massive gamble and luckily we avoided

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the need for Factor VIII treatment until the 1990's. However, I know it upsets her that she wasn't given better information for her to have made a proper informed decision about having children and she feels that she did put my brother and I at risk of serious harm.

3. The impact of being informed that I was possibly exposed to vCJD has had a huge impact on my psychological health. I received the letter in 2004 and I now feel that it was disgusting that I was not given the news face to face. At the time I became paranoid of getting ill and that continued for at least the following 2 years. There had been a lot of scaremongering stories in the press. I didn't eat a McDonald's burger for years which probably helped my health in the long run. I did try to not let it affect my social life or relationships too much however the impact on me as a young man at the time cannot be underestimated. Over time, as no symptoms developed, my worry did lessen somewhat. I remain very angry about the way I was told and left to process the information on my own. To give someone life changing information like this should not be done through a letter through the post. I still wonder why I have not received any further information or correspondence regarding the vCJD contamination even more so now since the Inquiry into contaminated blood products is now taking place.

6.Treatment/Care Support

1. I cannot recall having been offered any counseling or psychological support regarding vCJD. However, my hospital case records indicate my nurse practitioner, who undertook home visits when I was a young child, did offer general psychological support regarding having haemophilia at the time.

7.Financial Assistance

1. I have not received any financial assistance from any Trusts or Funds.

8. Other Issues

1. I have no further issues I would like to discuss.
2. I attach a small example of nine letters from my medical records from GRO-B to GRO-B

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Statement of Truth

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

Signed. GRO-B

Dated..... 8th May 2019