

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0563003

Exhibits: WITN0563004 - 006

Dated: 15th August 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4th April 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1962 and my address is known to the Inquiry. I am the daughter of GRO-B: M. I intend to speak about my mother who was a carrier of Haemophilia A and received Factor VIII during an operation, the Factor VIII was infected and this led to her contracting Hepatitis C.
2. I do not feel that legal representation is necessary at this time. I have also made a statement regarding the death of my brother GRO-B: B. GRO-B B was a haemophiliac and died in 1995 of AIDS and other complications, see GRO-B.

Section 2. How Affected

3. My mother took care of both my brother, [B] and myself while we were growing up. When I was born I suffered from epilepsy and [B] was a severe haemophiliac. My father subsequently discharged himself from the [GRO-B] to help my mother look after the both of us when [B] was diagnosed. Due to the severity of my brother's haemophilia, he required vast amounts of Factor VIII which led to him contracting both HIV and Hepatitis C as a result of infected blood products. My mother was a carrier of Haemophilia A, which meant that she needed Factor VIII before, during and after a hysterectomy operation. It is tragic that my mother became infected by the very same blood products that infected my brother. On discovering this, my mother [GRO-B] infected with Hepatitis C. My mother has since passed away.

4. I have provided a copy of her death certificate number [GRO-B]. It is dated [GRO-B] 2004 and signed by F.J. Bennet Registrar. It notes that my mother's cause of death was from a) metastatic breast carcinoma, although I would like it on the record that she in fact died from bone cancer. I exhibit this document as reference **WITN0563004**. I am perturbed and cross that this has been mis-recorded.

5. My mother was a carrier of Haemophilia A which caused her to have painful bleeds and reduced her ability to clot. In order to ensure that my mother's blood clotted, during a hysterectomy procedure, on 24th November 1983, in the Churchill Centre Hospital, Oxford, she received several doses of Factor VIII. She noted in her diary that on 22nd November 1983, she received 38 mls; 24th November 1983, 60mls; 26th November 1983, 85 mls; 27th November, 60 mls; 28th November 1983, 60 mls. She received these doses under the care of Dr Dasani.

6. I do not recall if my mother was warned of the risk of being exposed to infection via Factor VIII before it was administered to her.

7. My Mum only found out that she had contracted Hepatitis C, because of B insistence that she should get tested because of the quantity of Factor VIII she had been given. However, she got tested in March of 1995 after B had passed away and was told that she tested positive for Hepatitis C. I believe she contracted this infection from the batches of Factor VIII that she was given during her hysterectomy, in 1983.
8. From reading her diary of that year, it appears that Dr Copplestone told my Mum about her diagnosis. I am not sure what information was given to her regarding her infection or the precautions that should have been taken to reduce the risk of infecting others. Although, I do remember on one occasion my parents joking about having protected sex. I assume that other information would have also been given to her.
9. My mother did not have tattoos and she was not a drinker. Although, she did have her ears pierced from when she was little. My mother did not have promiscuous sex. It is highly unlikely that my Mum contracted Hepatitis C from these sources.
10. I think somebody should have said something to my Mum sooner, instead of my brother having to press her to get tested. Medical staff from the Churchill informed my brother of his HIV in 1982 and they informed him of his Hepatitis C infection in 1983. Staff at the Churchill regularly tested my mother's blood and she underwent her operation at the Churchill, in 1983 so they could have performed a 'look back' exercise and attempted to contact my mother, when she moved to Cornwall, in 1986. People travel with their NHS numbers; my mothers' number was GRO-B
11. To the best of my knowledge, Churchill never contacted my mother to inform her of the risks of infected Factor VIII or the risk of being exposed to Hepatitis C.

Section 3. Other Infections

12. At this time, to the best of my knowledge I do not believe that my mother acquired any infections, other than Hepatitis C contracted from her use of infected blood products. Obviously, unless someone comes up with another infection which is linked to contaminated blood, nobody is going to get tested for it, so therefore I cannot say for certain that she did not contract any other infection because of her use of infected blood products.

Section 4. Consent

13. I am not sure if my mother was tested or treated without her consent. I do recall that the Churchill Centre was very interested in our family because of [B] illness. My grandfather should have been a haemophiliac but he did not exhibit any symptoms. Both my mother and I, were carriers of Haemophilia A. Although, I only received this diagnosis after [B] death. Yet, when my Mum and I would accompany [B] to the Churchill centre, they would pull us aside and ask us to take blood tests so that they could check our bloods. We did not sign a consent form for these tests to be conducted. They justified these tests on the basis of checking our clotting levels. These tests occurred from 1971 to 1984. When my Mum moved to Cornwall, her blood continued to be tested but in Derriford Hospital.

Section 5. Impact

14. I am not entirely sure of the mental and physical effects that my mother encountered because of her infection with Hepatitis C. Although, I do know she developed liver problems and that she would get very tired and have to go to bed. She also got quite a lot of mini strokes. My Mum would also get in quite a muddle with her words, would suffer from confusion due to strokes. Shortly, after my mother received the all clear from breast cancer, she started complaining of pain on her right-hand side. Initially she was scheduled to see a specialist for a liver biopsy. However, when she saw, the specialist, Dr [GRO-B] he examined her right-hand side, just below

her ribs, and recommended that she should have a bone scan instead. The scan revealed that my mother was suffering from bone cancer which led to her death in [GRO-B] 2004.

15. I have included a newspaper article (exhibit **WITN0563005**) which details my mother's experience with her illness, where she stated:

GRO-B

16. I am not aware of her taking any tablets to treat her hepatitis however her diaries noted that she did receive Interferon. Although, my mother was similar, to my brother, she could not inject herself with inter-muscular injections, as her blood would not clot.

17. I am not entirely sure of the impact that Hepatitis C had on my mother's life. Although, from my mother's dairies, on the day she received her diagnosis she noted that '*I felt I was a disappointment.*' I would like to point out that my mother was infected with Hepatitis C through no fault of her own. I also know that later on she started [GRO-B]

GRO-B

18. The Hepatitis C infection did not really impact on my life. I took care of my Mum when she was ill with her bone cancer, which didn't have anything to do with the Hepatitis C as far as I am aware. I choose to look after her. I left work in the May and my Mum died in [GRO-B] We organised home carers to look after her, but my Mum was not entirely happy with them. My Mum was always an early riser so she would get frustrated when the carers would arrive at 10am. In the end, I took voluntary redundancy and became her full-time carer, which involved visiting her each morning, giving her a bit of space and then checking in on her again, in the afternoon.

19. I don't think my Mum told anyone about her hepatitis. My parents struggled with the stigma of [B] HIV diagnosis, so I imagine that she may have

found it difficult to cope with the stigma of Hepatitis C; my mother was a very private person.

20. I do not recall if Hepatitis C affected my mother's work life. My Mum retired just after my Dad died in 1997; she had worked part-time.

21. In the same newspaper article mentioned above, (exhibit **WITN0563005**). My mother also expressed her own sentiment of the impact of contaminated blood:

GRO-B

Section 6. Treatment/Care/Support

22. I do not recall my mother facing any difficulties in obtaining treatment. I know that my Mum went to the dentists every 6 months and that they wore rubber gloves. To the best of my knowledge, I assume that my Mum did not encounter any difficulties in accessing treatment. My mother's doctors in the GRO-B GP surgery were awesome and she had a very good relationship with them. Then, on my recommendation, she moved to Dr GRO-B in the GRO-B as she would take time to listen to our experiences of being a haemophilia carrier and how that affected some medical treatment.

23. My mother also received very good care from Dr GRO-B who was lovely. For instance, when my Mum was diagnosed with bone cancer, he immediately went to visit her and apologised.

24. To my knowledge my Mum was not offered counselling, for Hepatitis C neither was she offered any, during or after B death. I did receive some support, from a lady who worked with the Macfarlane Trust. This lady was a natural councillor who offered to talk to me after my Mum died.

We spoke on the phone on a number of occasions as she was based in London and I was in Cornwall.

Section 7. Financial Assistance

25. To my knowledge my Mum did not receive anything from any of the trusts.

Although, she did receive a one-off lump sum payment of £40,000 which I received through her estate. However, I had to sign a piece of paper that I could not pursue litigation if I accepted the compensation. This was a very traumatic period for me so I just followed the solicitors' advice.

26. I do not think that my Mum tried to obtain other forms of financial assistance, as she had her own money. I didn't even realise that she was entitled to any financial assistance.

27. I have not received anything directly as a consequence of my mother being infected with contaminated blood.

Section 8. Other Issues

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GRO-B

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GRO-B

30. I have been asked if there are any questions I would like to put to the inquiry. Why did they choose to go to America in the first place? The people who would want to give blood are probably going to be the ones who are going to spread infections. It just seems like such a stupid thing to do. The American system encourages those who are most disadvantaged and who carry infections to give blood to obtain money. I was also led to believe that in Scotland they were producing synthetic Factor VIII but they went to America because it was cheaper. To my mind that was wrong as well because that would have supported Scotland's economy which is part of the UK and that would have been a clean blood product. Money should not be an issue when it comes to someone's health and well-being.

Statement of Truth

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

Signed

GRO-B

Dated

15th August 2019