

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN3975001

Exhibits: 0

Dated: March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B**. I was born on **GRO-B** and I live at **GRO-B**.
2. My mother, **GRO-B: M** (born on **GRO-B**), was infected with the Hepatitis C Virus (HCV) through contaminated blood products. She contracted leukaemia and died on **GRO-B**, aged 64.
3. My brother, **GRO-B: B** (also infected with HCV), has provided his own Witness Statement to the Inquiry (under Witness Number **GRO-B**).
4. This witness statement has been prepared without the benefit of access to my mother's full medical records.

Section 2. How Affected

5. My mother had *mild* Haemophilia B (also known as Christmas disease). I was just a baby when she was diagnosed with haemophilia. She was 29 years old and had just had all her teeth extracted. My two brothers have *moderate* Haemophilia B. My mother's clotting factor levels were much higher than my brothers at 17% but she suffered a lot more with bleeds. She was often in and out of hospital.
6. My mother was treated at the Leicester Royal Infirmary (LRI). Prior to that I believe she attended at one of the London Haemophilia Centres. My mother and brothers were treated with Factor IX (FIX) blood concentrate.
7. I do not think that my mother was provided with any warnings about any risks associated with blood products. She thought the FIX concentrate safe to use.
8. My mother was told that she was infected with HCV in 1991 or 1992. B was told that he too was infected with HCV around the same time. I do not think that they were given much information to help them to understand and manage their infections. My parents did not behave any differently. Their relationship carried on as normal. We hugged and kissed. My mother did not keep her own personal items/toiletries separate to ours. My mother was unclear as to what it meant to be infected with HCV. I remember her being more worried about B than herself and it was horrendous for her. She blamed herself for having haemophilia, for passing it on to us and for B being infected with HCV as a result.

Section 3. Other Infections

9. I do not believe that my mother was infected with anything other than HCV.
10. I am a haemophilia carrier and my son (now aged 25) has haemophilia. My mother and son received notification of possible vCJD exposure in the early

2000s. It has been a waiting game but my husband and I heard nothing more since in relation to my son. Thankfully, my son had just a couple of treatments before he went on to Recombinant factor but my mother had very many.

Section 4. Consent

11. I am unable to say whether or not my mother was ever tested or treated without her knowledge and consent.

Section 5. Impact of the Infection

12. I remember the fear and worry surrounding the HIV/AIDS scare in the 1980s. The fear and worry for my parents and my brothers about HIV was the first concern about their treatment that I personally remember. There was a period of approximately six months in the mid 1980s during which we had to wait to find out whether my mother and brothers were infected. It was a massive fear for the family and particularly my mother who was not just worried about herself but her two sons.

13. When I was in my teens my school friends knew that we were a haemophiliac family. They asked a lot of questions about whether we were infected. I had a lot of unwanted attention and I was made to feel very uncomfortable.

14. After being tested and diagnosed with HCV, my mother trialed the Interferon and Ribavirin treatment. She was on the treatment for a significant period of time, possibly 9 months to a year. There was no guarantee that the treatment was going to be successful. It did eventually clear the HCV infection but it made my mother incredibly poorly. My mother suffered with rheumatoid arthritis and had to have an increased dose of steroids. The rheumatoid arthritis flared up to chronic levels within weeks of starting the treatment.

15. My mother became crippled with arthritis. My mother was a dignified and very independent person. My son was very young and I became responsible for my mother's personal care, helping to get her out of bed in the morning and in and out of the bath. She cried so much with the pain and it was horrendous for her but she was determined not to give up as was going through the same treatment and she didn't want him to give up. It was a battle they were fighting together. She never moaned or felt sorry for herself. Her only concern was . The combination treatment was believed by the doctors to be the cause of the flare up because nothing else had changed and within a within a matter of weeks of completing the treatment the rheumatoid arthritis had settled down again.

16. After completing the treatment my mother went on to develop a lung condition which caused fibrosis of the lung. She also developed brittle bones and had two major breaks, one to her leg and the other to her hips. My mother really struggled with a whole raft of health issues after the treatment. She didn't deserve any of it. I was working as a food logistics co-ordinator whilst trying to care for her. She needed oxygen cylinders to get out and about and she tried to maintain some independence for as long as she could. My mother received a Stage 1 Skipton Fund payment and was in communication with them about whether the Interferon had caused the fibrosis. Before we could get answers, we lost her to leukaemia. My mother died within four weeks of diagnosis. She couldn't cope any more and seemed to give up. She was only ever concerned about not herself. We lost a Mum and a Nan and as a family we were left devastated.

17. My mum suffered both mentally and physically, infected with HCV because she needed treatment for her haemophilia. I am now mistrustful of the medical professionals in relation to my son's haemophilia care. I can completely understand why it is that my mother had such a deep feeling of guilt in relation to her own son. A few years ago my son had a bleed behind his eye and almost lost his eye sight. As a mother myself, I have an insight as to how my own mother felt. As a carrier, I too blamed myself.

Section 6. Treatment/care/support

18. I do not believe my mother was offered any form of counselling or psychological support. I believe that she would have taken it had she been offered it.

19. I was never offered any counselling. There was never anyone to talk to. Because of the stigma of infection, everything was 'hush hush' at the time. I knew I needed to protect my mother and brother.

Section 7. Financial Assistance

20. My mother received the Stage 1 Skipton Fund payment.

21. She did not receive any other financial support and she was forced to retire in or around 2000 because she had become oxygen dependant. She had to live on a modest pension and disability benefit because of the condition of her lungs.

Anonymity

22. I wish to remain anonymous.

23. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-B ...

Dated 20.04.2020