

ANONYMOUS

Witness Name

GRO-B

Statement No: WITN3635001

Exhibits:0

Dated: September 2019

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** 1983 and I live at **GRO-B** I am married with three children, **GRO-B** I currently work full time as a registered nurse.
2. I make this statement in relation to my late father **GRO-B: F** who was born on **GRO-B** 1959 and who died, at the age of 38, on **GRO-B** **GRO-B** 1997. My father was infected with Hepatitis C (HCV) and the Human Immunodeficiency Virus (HIV) as a result of receiving contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my late father's full medical records.

Section 2. How infected

4. My mother, GRO-B
GRO-B has also given a statement to the Inquiry. This provides a more detailed account of how my father was infected as I was too young at the time to remember.
5. My father had severe Haemophilia A which was diagnosed with when he was around 2 years old. His family had a history of Haemophilia.
6. When my father was young he received Cryoprecipitate (Cryo) to treat his Haemophilia. He then moved on to Factor VIII concentrate (FVIII) which he administered at home after being taught how to inject himself. I remember seeing vials of medication which were kept in our fridge at home.
7. My father was treated at the Haemophilia Centre at the Manchester Royal Infirmary (MRI). His consultant was Dr Wensley.
8. I do not believe my father or his parents were ever told that there was any risk in relation to receiving any blood products.
9. As a result of watching a Panorama documentary my father realised that he may have been at risk of infection. He collected together all of his FVIII, put it in a bag, and took it to MRI. He told them he would not be using it anymore and if he had a bleed he would come into the hospital. He also said from that point onwards he only wanted to be treated with Cryo.
10. My father was diagnosed with HCV, then known as Non-A Non-B Hepatitis and HIV a few months after the documentary which was televised in 1985. He went to the hospital for a check up and he was told in passing that he had been infected. I believe he was told he had both viruses at the same time.

Section 3. Other Infections

11. The only infections I am aware that my father had were HIV and HCV.

Section 4. Consent

12. I do not know if my father was treated without his knowledge or consent. I do not know if he was treated for research purposes.

Section 5. Impact of the Infection

13. I remember my father being in hospital a lot but I did not really understand why he was poorly. I know that he had had a liver transplant when I was around 10 or 11 years old.

14. I was looked after by good neighbours and family friends on numerous occasions as my father was in and out of Edinburgh Royal Infirmary Hospital. When my father was having his transplant in London my mum was away for a couple of weeks so my Nan and Grandad came to the house and looked after us there for a few weeks.

15. About a week before my father died I went to the hospital and he sat me down and said 'be very brave for your mum next week because I won't be here; I love you very much'. I was aged 13 at the time but I remember it so clearly. I knew he was very ill but it was normal for him to become poorly and then pick up again so I just assumed he would be home again in a little while. I thought this time would be no different; I couldn't quite believe it. He spoke to my sisters individually and said this time he would not be coming home. I was shocked; I couldn't quite believe it.

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16. Mum said he was coming home on the Saturday but I did not grasp that they were planning to bring him home to die. However, he never got the chance. I last saw my father on the Thursday night before he died.
17. I remember the morning my father passed away very clearly. Mum was getting ready to go to the hospital to collect my father to bring him home. The phone was ringing and at the same time the dog was barking. It was all a bit strange. Mum missed the call and when she had finished getting ready she said that she had a strange feeling. She phoned the hospital to see how my father was and she was told that he had died. Mum got my sister and I together and told us our father had died. My eldest sister **GRO-B** was not there at the time. I went to my father's funeral; I was devastated. That day is just a bit of a blur. I think I just blanked it out.
18. I had some time off school but I cannot remember exactly how much. I was 13 at the time and his death affected my concentration and ability to focus at school. I had just started the two year standard grades course. I took my exams but the grades were not as good as what I had been expected to achieve. As a result I left school and went to college and studied science there.
19. I then worked as a health care assistant for a few years to get experience to see if I really wanted to go into nursing. I had always thought I would go into that line of work and my father had encouraged me. He was a doctor and when he worked at the **GRO-B** Hospital he would take me along. There was a ward for older ladies and gentlemen who did not have many visitors so I would go and chat with them and keep them company. It was great experience and I always liked watching the nurses thinking that I could do that job.
20. I did my nursing degree at the University of Dundee which took 3 years and I qualified in 2011. I put everything into it. I was married at the time and had 2 very small children. It was hard work but I got there in the end. I was very determined to be successful. I got to my goal eventually but I think I would

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have got there sooner if my father had not died. I am lucky to have a supportive husband and family.

21. My father died during an important part of my life and I did rebel as a teenager. I started drinking alcohol underage as a way of coping. I do not think I would have gone down that path if my father had still been alive.
22. My father did not drink or smoke and he had a healthy lifestyle. He did everything in the right way. He looked after himself and yet he was still so ill. My father should still be here. I think of everything he has missed out on and it's just not fair. Every single family event, including graduations, christenings, birthdays, and anniversaries are hard because he is not there. It does not matter how many years have gone by it is devastating to think he is not a part of those celebrations.
23. I got married on GRO-B I was devastated on my wedding day. Whilst such a happy day and I am very fortunate to have such a supportive husband, it was tinged with sadness because I did not have my father to give me away.
24. My eldest son GRO-B has severe Haemophilia A. I was terrified because my father had died as a consequence of the treatment he had for his Haemophilia so when I was told my son needed to go onto prophylaxis Factor VIII treatment I was petrified he would be given the same fate. It took a lot of support from the Haemophilia Centre to reassure me that the product I was injecting into my son was not the same as that which had been injected into my father.
25. GRO-B was about two months old when he was diagnosed and started prophylaxis at the age of one. It was very difficult to get veins on him so he had a porta cuff fitted for easier access. I was reassured that the Factor VIII treatment he received was synthetic. Everything at that time had been taken over by the Haemophilia Centre and they would oversee everything. The

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nurse specialist treating GRO-B remembered Dad and knew about my concerns with GRO-B; she reassured me.

26. GRO-B knows that his Grandad had Haemophilia. He did not know about the infected blood products or why he died. We have decided not to tell him as I do not want my son to be frightened about having his treatment. He could have benefitted hugely and would have had a great amount of support from his Grandad. I know Dad would have taken GRO-B under his wings. He has missed out on his grandchild and my three children have missed out too; never having met their grandad.

27. Apart from my husband I have told no one how Dad died. There is a stigma associated with Haemophilia. GRO-B has only told the school and a few close friends, as he got older, about his own diagnosis. There is a lot of media coverage about Haemophiliacs contracting Hepatitis and HIV. I do not want that stigma and the ignorance attached to make people think that my son has Hepatitis and/or HIV. Therefore, we do not make his Haemophilia common knowledge. It is a private family matter.

Section 6. Treatment/care/support

28. I was not offered any care or support after my father died.

29. I did not ask for any support when Dad died as being 13 years old I would not have known to have asked.

Section 7. Financial Assistance

30. I was very aware of the financial strain my father's illness and death had on my mum. We grew up in a lovely family home in GRO-B but she could not

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afford to keep the house. She had no option but to sell it. It took a while to sell and she struggled to sell it. I remember some months when my mum had no money at all. She was working as a health care assistance in a local nursing home and she had to get an advance on her wage to buy food for us. One winter the boiler broke and we all sat in the living room with coats and duvets as she had to wait to get paid before she could get the boiler fixed.

31. Since my father died Mum has always struggled financially. She downsized and moved to a smaller house which did ease some of the financial strain but she has always had to watch her money. She went from being a house wife on a doctor's wage to having to look after her family on a minimum paid job. She has always struggled to make ends meet.

32. If I remember correctly I am sure there was a benevolent fund and I received a couple of hundred pounds from it when I started college so that I was able to buy books. This was because Mum was on a low income. I am not sure if it was to do with how Dad died or a widow's payment. Other than this I have not received any other financial assistance and I am not aware of what other financial assistance my mother has received.

Section 8. Other Issues

33. I would like my mum to be acknowledged. She has had a lot of years where she has struggled financially and she is the loveliest person. Even when my father was here she put her life on hold to look after him and to drive him back and forth to the hospital. My mum deserves financial assistance. It is not going to bring my father back but it might make her life a little bit easier.

34. I would also like an apology.

Anonymity, disclosure and redaction

35. I confirm that I do wish to apply for anonymity. I understand this statement will be published and disclosed as part of the Inquiry. I would wish to give oral evidence to the Inquiry if called to do so.

Statement of Truth

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

Signed.....

GRO-B

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GRO-B

Dated.....15/11/19.....