

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3383001

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 1936 and I live at GRO-B.
2. My husband, GRO-B: H (born on GRO-B 1933), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products. He died from hepatic failure (liver failure) on GRO-B 1987, aged 54.
3. I have five children, two boys and three girls. I have nine grandchildren and one great grandchild. Just one of our nine grandchildren, namely GRO-B, was born before H died.
4. This witness statement has been prepared without the benefit of access to H's full medical records.

Section 2. How Affected

5. [H] had severe haemophilia A. He was diagnosed when he was 4 years old. He was the eldest of six siblings and his mother did not know that she was a carrier. [H] was literally carried around on a velvet cushion out of fear of him being injured and/or bruised. I think that his mother must have had a hard time of it as she could only listen to her children crying if they were in pain from a bleed. [H] was not well for all his life but he just got on with it.

6. [H] and I were married in 1961. He was treated at the [GRO-B] Haemophilia Centre at the [GRO-B] Hospital under the care of Dr [GRO-B] [GRO-B]. He was treated with plasma and then, as I recall, with cryoprecipitate before being treated with Factor VIII (FVIII) concentrate.

7. I wanted to be a nurse as I was growing up. My father wasn't keen. My parents would have preferred me to be a teacher. I lost both my parents when I was 17 years old and as I was the eldest of four, I had to leave school to bring the younger three up. In a sense, I did become a nurse because I nursed [H] and learned how to give him his injection at home. When [H] went on to FVIII concentrate I would administer it to him at home. I had no difficulty with that. I was well able to find a vein and administer it.

8. No information or advice was provided to me or [H] beforehand about the risk of being exposed to infection from blood products. When FVIII concentrate became available to [H] it was like a new lease of life. The home treatments meant that he would not have so many hospital admissions. It became a bit of a joke in the family that other people had food in their fridge, while we had FVIII concentrate in ours.

9. [H] was informed that he had been tested positive for HIV and Non-A Non-B Hepatitis (NANBH) in June 1985 by way of letter from Dr [GRO-B]. [H] didn't

really say anything about it. I picked the letter up and asked "What does this mean?" We never really spoke about it again. However I do recall Dr [GRO-B] asking [H] a short time later if he would go on TV and speak about it. I remember saying "No way are you going on TV and exposing yourself". HIV/AIDS was hitting the media around that time and everyone was afraid of it.

10. We have only recently learned through a letter written by Dr [GRO-B] in 1990 that from clinical information available to her, it is likely that [H]'s HIV seroconverted in May 1983.

Section 3. Other Infections.

11. [H] was not infected with anything other than HIV and NANBH/HCV.

Section 4. Consent.

12. [H] may well have been tested for HIV and NANBH/HCV without his knowledge and consent. Many blood tests were done on him without specifically telling him why they had been taken at that time.

Section 5. Impact

13. My memory has faded with the passage of time but I can recall an appointment with Dr [GRO-B] after receiving [GRO-B] letter informing us that [H] had been tested positive for HIV and NANBH. I remember [GRO-B] shaking [GRO-B] head and saying "We do not know what will happen now". I also remember us discussing whether [H] should take a certain tablet/medication as a treatment option. I remember [GRO-B] saying these actual words: "No, this would blow him [H] into kingdom come".

14. [H] was a great man. He was a very successful auctioneer and antique dealer. He was at one time head hunted by [GRO-B]. When he closed his [GRO-B] at the height of the Troubles in [GRO-B] he went to university and obtained his degree. He trained as a social worker and worked with children who were disabled. A person who has suffered (and [H] suffered all his life) understands the suffering of others.
15. [H]'s work colleagues at Social Services were aware that [H] was a haemophiliac. The [GRO-B] family were known as haemophiliacs ("bleeders") in the wider community. When the news of HIV/AIDS broke in the community, [H] was ostracised at work and made to feel very uncomfortable. I do not now remember all the ins and outs but I remember [H]'s boss and one of his work colleagues coming to our house about [H]'s health status. I was angry and gave them the sharp end of my tongue, saying "pity for you" that they *had to* come out to us. In short, [H] ended up having to leave his job.
16. [H] was used to being unwell all his life and didn't complain. His health went downhill quickly from diagnosis although he was, I think, showing signs of being unwell before then. He became weak and tired and thin.
17. I remember when [H] was admitted to the [GRO-B] Hospital for the last time at the start of July 1987. The other patients on the ward were immediately moved out. In the end, it was only [H] left in the room and we rarely saw a doctor or nurse from one end of the day to the other. It felt like all the staff had just disappeared. After about three weeks in the [GRO-B] I phoned our family doctor, Dr [GRO-B] to tell him we were bringing [H] home. Dr [GRO-B] warned us that [H] could die on the way home. I was terrified but we brought him home anyway.

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18. We had about two more weeks nursing [H] at home before his final admittance to [GRO-B] Hospital. He was bleeding from the stomach and vomiting blood. I wanted to nurse [H] at home. Dr [GRO-B] said he couldn't cope with [H]'s care. I said "I can!" but he insisted that [H] be admitted to hospital. Once again, we felt very alone and isolated in the hospital room. All the medical staff appeared to be afraid to even come in to the room. At one point, a male nurse actually ran out of the room while [H] was taking a fit. The sister on the ward did not come near us at all until the final few moments before [H] died.
19. I had not left [H]'s side since the beginning of July and I was nearly not there when he died. Just about 5 minutes before [H] died, I was called out of the room by the sister. She told me that when [H] died, we would have only one hour with him and then he would be taken out in what amounted to a black plastic bag before ultimately being placed in a sealed coffin. My daughters, [GRO-B] and [GRO-B] had to send for me so that I could make it back to the room to be with him when he passed. I couldn't believe her lack of sensitivity.
20. [H]'s coffin was sealed, not open for our family to say goodbye as is the tradition. It was terrible for us.
21. [H] was a deeply religious and spiritual man. He had great faith and celebrated mass daily. [H] was the [GRO-B]. Sixteen priests presided over his funeral with maybe another forty attending. He was an articulate and insightful man, [GRO-B]. [GRO-B] He was selfless and had a deep social conscience. He would share whatever he had with those who had nothing. Whatever was in the fridge he would come and take and give away to others in more need. He once gave away the turkey I had cooked for our Christmas dinner to a family with nothing.

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22. [H] loved music. He loved life. He loved his family and his granddaughter [GRO-B] whom we saw a lot of. I was widowed at the age of 51 and three of our children were still in their teens.

23. I have never got over the loss of [H]. I have never talked openly and fully about it. I am frightened to open the flood gates because once they are opened they cannot be closed.

Section 6. Treatment/Care/Support

24. [H] was not offered treatment and/or counselling.

Section 7. Financial Assistance

25. I do not recall the specifics but I did receive a payment from the MacFarlane Trust (MFT). I do not remember how much. I don't think it was much. I once wrote to MFT because the roof needed fixing. They turned me down.

26. I received the Stage 1 and Stage 2 Skipton Fund payments just 5 or 6 years ago. A man I didn't know approached me in the street and said that Dr [GRO-B] at the [GRO-B] Hospital was looking for me. I would not have otherwise known about the Skipton Fund but I was outraged that a virtual stranger appeared to know about [H]. At that time, Dr [GRO-B] had [H]'s notes on his desk and he said that "they made for very sad reading". I wished I had asked for them there and then because I am now given to understand that [H]'s notes may have been destroyed. We are in the process of trying to get hold of them.

Section 8. Other Issues

27. There are no other issues.

Anonymity, disclosure and redaction

28. I wish to apply for anonymity and would like my Statement redacted. I understand this Statement will be published and disclosed as part of the Inquiry. 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..... 20th December 2019