

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3887001

Exhibits: WITN3887002

Dated: February 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
GRO-B
2. My father, GRO-B: F (born on GRO-B, was infected with the Hepatitis C Virus (HCV) from contaminated Factor VIII (FVIII) concentrate. He developed end stage liver cirrhosis and died on GRO-B
GRO-B 2000, aged 68, after his lung was punctured by his rib from a fall.
3. This Witness Statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How Affected

4. My father had mild Haemophilia A. He was the first known haemophiliac in his family and his haemophilia diagnosis came as a shock to my grandmother. I am a carrier of Haemophilia and I have a daughter.

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5. My father was under the overall care of Professor Flute at the Haemophilia Centre at St George's Hospital in London. He was also seen and treated at St Luke's Hospital, Guildford and the Royal Surrey Hospital, Guildford under Dr Douglas.
6. My father was treated with FVIII concentrate on an ad hoc basis as and when it was needed for bumps and knocks. Typically, he needed treatment every two to three months; sometimes monthly.
7. My father, mother and I had no idea that my father had HCV until 25th August 1998 (just two years before he died). My father's health had deteriorated a lot by then. He was also feeling very fatigued and he was drinking a lot of liquid because he was always thirsty. My father was tested for diabetes (at my mother's instigation and with some persuasion because he was reluctant to go for the test) and my parents' GP, Dr GRO-B telephoned my mother with the results. She said 'we are very sorry F does have diabetes and he also has hepatitis C'. My mother was the one to have to relay to my father what the GP had just said about him being infected with HCV.
8. We had very little understanding of what HCV was and there was no information provided to him or my mother. We knew it was something serious but my parents (being aware that AIDS was a killer) were thankful that my father didn't have HIV/AIDS. They thought HCV was not so bad. The severity of the infection wasn't explained. My parents were asked to come in for a meeting but that in itself was a difficulty as my father was wheelchair bound in the latter years of his life and only went out for hospital appointments (in an ambulance).
9. We were subsequently told that the FVIII treatment my father first received in the 1970s/1980s had caused the infection. Dr GRO-B said that my father had probably had HCV for very many long years, possibly more than 20 years but had not shown in his system until then. My father had developed liver

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damage but he didn't drink alcohol. Apparently, there was nothing they could do about it. It was too late for treatments which may have helped in some way to prolong his life. Dr Douglas said an operation was not possible as my father would not be able to withstand the same operation that a younger, healthier person would be able to cope with. My father was ill with lots of health issues to include arthritis and the newly diagnosed diabetes. My father's hips had been systematically worn away through all the bleeds he had endured and the resulting arthritis. My mother and I could do nothing to help my father except to carry on as normal.

10. When my father was first treated with FVIII, he was told it came from the United States but was not made aware of the source. He had no choice in the matter. FVIII was 'sold' to him as the new wonder drug that would 'save his life'. No-one warned my father about the risk of infection. No-one said anything about it. If he hurt himself he went to the Haematology Department at the hospital and he trusted them there.

Section 3. Other Infections

11. My father was not infected with anything other than HCV.

Section 4. Consent

12. I do not believe that my father consented to being tested for HCV. We thought he was being tested for diabetes and the HCV diagnosis came 'out of the blue'.

Section 5. Impact of the Infection

13. My father was a strong-willed, determined, hardworking and resilient man. He worked as a milkman in his younger days and then carried on at the dairy loading the carts and seeing the milkmen off on their rounds. He had polio as a child and had lost the use of his left arm. He didn't make a fuss about that. He did not like the thought of taking money from the state by way of benefits.

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He was a very proud and private person and didn't tell his work colleagues that he had haemophilia. He worked for as long as his health would allow, probably up until the mid to late 1980s. Some time after that my mother gave up work to look after him and, in effect, became his carer.

14. My father loved sport and particularly horse racing. He was told not to ride a horse or play sport as a young boy and loved anything to do with horses and sport as a result. He enjoyed watching horse racing on television and would scour the runners in the Daily Mirror on a Saturday morning in order to place his bets for the day. As his health deteriorated my mother would 'run' his bets up to the bookie. In the last two years of his life, after he was told that he had HCV, that stopped too and all he could do was to lie in his recliner chair (funded by my work) in front of the TV. He no longer wanted to go out, not even into the garden (with our help and encouragement) on a nice day. He became very reclusive and didn't want anyone to visit him. He did not want people to know that he had HCV. He became very depressed and anxious and he just wanted my mum. Towards the end of his life my mother had to put a hoist over the bed as she just couldn't lift him alone. The two of them became very isolated.

15. After the HCV diagnosis, my father suffered with bruised, sore, painful and swollen arms and legs that blistered. He was in a great deal of pain. I refer to Exhibit WITN3887002 being photographs of his arms. One arm (the one paralysed from polio) was left untreated. It was awful to see.

16. I was working. My husband travelled a lot for work and I had a young (4 year old) daughter to care for. I would go and see my mother and father most days on my way home from work. I tried to maintain as much normality as possible but we were such a small unit. Towards the end, my father was often just asleep in the chair, not even realising I was there. He was on a lot of medication. Despite being in great pain, my father was not reviewed or monitored on a regular basis by any doctor. After my father took a fall at home hurrying to try to get to the toilet (falling on my mother in the process),

he was hospitalised. I remember clearly and with great sadness that my father was isolated in a room on his own with a tape across the door like he didn't (or shouldn't) exist. I would go to visit my father and the tape was what I was confronted with at his door.

17. My mother stayed with my father in that room for the last 10 days of his life and looked after him 24/7. He could not even be x-rayed because his body was so full of blood but his lung was punctured by his rib when he fell and there was no hope for him. He (briefly) opened his eyes just once and they were bright yellow in colour. They stopped all treatment apart from diamorphine. My father died in the most painful and undignified way possible on the GRO-B 2000.

Section 6. Treatment/care/support

18. My father, mother and I were never offered any counselling. I am ordinarily strong and stoic like my father but I hit a brick wall and broke down some six months or so after my father died. I had counselling then but had to seek it out myself. Up until then we still had so much to deal with to include arranging and paying for the stair lift to be taken away and taking care of my mother (who came to live with us for some months). Six months later I couldn't deal with it all anymore and I crumbled.

Section 7. Financial Assistance

19. My parents (and I) had no financial support from the trusts and funds. They struggled financially and were reliant upon disability benefits and carers allowance. I helped them financially as much as I could from my salary. They didn't have very much money at all and there was no one else to help.

Section 8. Other Issues

20. There are no other issues.

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Anonymity

21. I wish to remain anonymous.

22. I do not wish to provide oral evidence to the Inquiry.

Statement of Truth

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

GRO-B

Signed.....

Dated 25.08.2020