

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2947001

Exhibits: 0

Dated: APRIL 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 and I live at GRO-B
GRO-B I am married with two young daughters and I am, by occupation, a self employed Financial Advisor.
2. My father GRO-B: F was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products. He died from Acquired Immune Deficiency Syndrome (AIDS) on the GRO-B aged 51.
3. My mother has provided her own Witness Statement to the Inquiry
GRO-B
4. This witness statement has been prepared without the benefit of access to my father's medical records.

Section 2. How Affected

5. My father had severe Haemophilia A. He was diagnosed at birth through bleeding from the umbilical chord.
6. My father was treated at various Haemophilia Centres to include St Bartholomew's Hospital, the Kings College Hospital and St Thomas's (and Guy's) Hospital. My father was under the care of Dr Cathrie and Dr Clark at St Thomas's (and Guy's) Hospital. Latterly he was cared for by Dr Savidge.
7. I believe that my father was treated with plasma, fresh blood and cryoprecipitate initially. He was given Factor VIII (FVIII) from the early 1970s. I understand that my father first tested HIV positive (from a blood test) in January 1985.
8. I found out that my father had HCV after he died and my mother applied for a payment from the Skipton Fund. My father was told that he had non A non B (NANB) Hepatitis at some point but my parents did not understand or appreciate that NANB was (and later became known as) HCV. My father developed liver problems and was under the care of a liver specialist, Dr Trowell, at the Oxford Churchill Hospital.

Section 3. Other Infections

9. I do not think that my father had any other infections than HIV and HCV.

Section 4. Consent

10. My father was tested without his knowledge and consent. He was tested HIV positive at University College Hospital in January 1985. He must have been tested for hepatitis but was not given adequate or full information in relation to it.

Section 5. Impact of the Infection

11. When my father was told that he was HIV positive, it didn't mean a lot to me. People knew so little about HIV at that time (1985). It may be that as my sister and I were young, our parents kept a lot of it from us. We were all in the dark but I know that there was no plan of treatment available. I remember my father saying that FVIII blood concentrate had come from prisoners in the USA. He said that on more than one occasion.
12. Over a period of time, HIV/AIDS became part of the mass media with programmes on television like World in Action stories in the newspaper. We couldn't tell anyone outside the family that my father had HIV. We kept it to ourselves.
13. I remember my father looking jaundiced. He also became very confused like an old person with alzheimers. The confusion got worse over time and was one of the hardest things to deal with. We knew that my father had a liver condition but we did not know until after he died that he had HCV. We did not know that my father's confusion (hepatic encephalopathy) was caused by my father's damaged liver.
14. In August 1989 my father was hospitalised having contracted PCP pneumonia. From that time until his death in GRO-B 1991, his health started to go downhill quickly with the onset of full blown AIDS and confirmation that my father had cirrhosis of the liver. It seemed to be one thing after another with my father's health issues. He was fighting a constant battle of hospital visits with little or no answers. Just as he would get over one health complication, he would be hit with another. My father's personality changed as he was suffering with chronic fatigue and depression in addition to his confusion. I used to see him cry a lot when he had not been like that before. He was previously a man's man before and kept a 'stiff upper lip'. He became worn down from the various illnesses.

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15. My father was again admitted to hospital in GRO-B 1990 with a collapsed lung from PCP pneumonia and died within a few weeks. His body was overwhelmed with the various infections caused by AIDS.
16. I remember a prominent newspaper story with photos (maybe in The Sun) at around the time of my father's death about undertakers turning up at the death of an AIDS victim with masks on. My mother was really worried about experiencing the same treatment. We went to our local, well established undertakers and I asked as soon as we arrived "My father has died of AIDS, is there going to be a problem? If it is, we will go somewhere else". We were told 'no, but that they cannot embalm him' which was fine but it was a real concern for us.
17. Because of the stigma associated with HIV there was effectively no grieving process for us. When you lost someone to AIDS at that time it was hushed up by the Government/authorities and the families were happy to go along with that. With social media as it is now, the news of the suffering and/or death of so many from a mystery disease would be shared with others affected and they would be able to communicate with each other for information and mutual support. We told everyone my father had cancer (after his death). We could not properly open up to other people. I returned to work and life had to go on. My work colleagues knew that my father was in hospital and that I was visiting him but they were shocked when I told them that my father had died. Most people's reaction was "oh I knew he was in hospital, but I didn't know he was that unwell". My father's death hit me hard about a year later.
18. I did not tell anyone that my father had AIDS for years. It has only been within the last 10 years that the tragedy of the infection has been acknowledged in the media and more sympathetically understood. My mother still worries to this day about the stigma.
19. We grew up on a council estate. Many of our neighbours were able to move away and/or buy their own homes through the right to buy scheme. My father couldn't get a mortgage because he could not get life assurance. Towards the end of my father's life he could not work. This had a big impact on us

financially that continued after my father's death. It was particularly hard for my mother.

20. We were a very close knit family and I had had a very close relationship with my father. We were a part of a community in GRO-B London. Before my father became ill and was unable to work, he was a GRO-B Newspaper Delivery Driver which (a closed union occupation). My father had the freedom to work when he wanted (and around his haemophilia bleeds) which meant that he usually worked Friday, Saturday and Sunday nights (the most lucrative shifts). As a result he was always around for us. He was there to take me to and from school and was around at meal times. I took it for granted he would always be there.

21. I was 22 years old when my father died and it was a huge loss to me. I lost my guidance and my mentor and I was left with the responsibility of a mother widowed at a young age and a sister approaching 16 years old going through all the associated trauma of a teenage girl. It was a tough home life and the ripple effect of the loss of my father went on for years. It distorts things for ever. My wife has her own father around her and our children have just one grandfather. My mother was robbed of companionship in her later years with my father.

Section 6. Treatment/care/support

22. My father took part in an AZT trial. He did not have any treatment for HCV.

Section 7. Financial Assistance

23. My parents struggled financially because my father became too sick to work. My mother could not work. My father needed her by his side and my sister was still at school. They relied on benefits and a small income from the MacFarlane Trust.

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24. After my father's death my mother received Stage 1 and Stage 2 Skipton payments.

25. After my father's death my sister received a payment from the MacFarlane trust but I did not receive anything, I believe this was because I was 22 years old at the time.

Section 8, Other Issues

26. There are no other issues.

Anonymity, disclosure and redaction

27. I am seeking anonymity and would like my Statement redacted before publication. However 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

Dated29/4/19.....