

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN3490001

Dated: 14th July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26th June 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, **GRO-B** make this statement true to the best of my knowledge and belief and will say as follows: -

1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is known to the Inquiry. I live with my parents, **GRO-B:F** and **GRO-B** and my **GRO-B** at our home in **GRO-B** **GRO-B** I currently work full-time as a **GRO-B**

2. I am providing this statement as the affected **GRO-B** of **F** **F** who was infected with hepatitis C through contaminated blood. I will explain how my father was infected and in particular how his infection and subsequent illness affected me and my family.

2. How Affected

1. My dad is a mild haemophiliac suffering from haemophilia A. My dad was treated on a number of occasions with Factor VIII blood product. These treatments took place at the **GRO-B** in **GRO-B**. I am aware that Dad had some health problems in the early **GRO-B**. He was involved in a road traffic accident and suffered swelling around his abdomen. When a biopsy was taken he was given a diagnosis of Non Hodgkin's Burkitt's lymphoma. In hindsight, he now knows that this was related to his hepatitis C infection, which at the time had not yet been identified.
2. Dad found out that he had hepatitis C in **GRO-B** when the Haemophilia Society informed haemophiliacs that some people may have been infected with contaminated blood. He was given an appointment to see Doctor **GRO-B** at the **GRO-B** following which he was diagnosed with hepatitis C. He was told at the time that he had been infected by contaminated blood when he had a tooth bleed in **GRO-B**. There was also a suggestion that he had been given contaminated blood in **GRO-B** when he had a **GRO-B** injury.

3. Other infections

1. I am aware that my dad was informed that he may also have been infected with variant CJD.
2. My dad has also suffered from fibromyalgia and arthritis which may be linked to contaminated blood.

4. Consent

1. My dad was quite young when he received the contaminated blood products but as I understand it, neither he nor his mother were informed of any problems or risks associated with the blood products he received.

5. Impact

1. My first recollection of my dad being unwell was when he stopped working and started to be at home all of the time. I was just a little girl then but I recall watching him to begin to become very frail. I would describe him as an old man in a young man's body. I recall when I was around [GRO-B] years old that he looked so unwell that people would comment on his [GRO-B] which was really [GRO-B] I remember when I was about [GRO-B] years old and just beginning [GRO-B] I was so worried about Dad that I would intentionally miss the bus to school because I didn't want to go in case anything happened to him whilst I was there. Even at that young age I felt a responsibility to try and make sure Dad took his tablets. I remember trying to persuade him to take sachets called Hepamertz which removed the toxicity from his blood. I believe this was around [GRO-B]
2. I remember at home that there was always a 'sharps box' for Dad's injections that I was told not to touch. I also recall being told from a very early age not to touch his tablets and not to try and help Dad if he cut himself. At the time I would not have understood why we had these rules in our house nor would I have found it unusual.
3. I started [GRO-B] in [GRO-B] I remember being bullied a lot by the other children who accused my dad of being an alcoholic. Even the teachers would make comments about my dad, his health and what they thought was a drinking problem. On one occasion, I was in an English lesson and I was perhaps not paying attention due to the distraction of my difficult home life at the time. My English teacher said that I would never amount to anything. I assumed she meant this because of her perception of my dad's illness. At the time I was so upset and angry that I pushed over a table and screamed at her. I told

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her that my dad had contracted hepatitis C from contaminated blood. It was only after this incident that teachers started to treat me differently.

4. I was sent to see a school counsellor on one occasion but did not find it useful. The counsellor did not fully understand what had happened with my dad and actually seemed more interested in trying to get information from me for the purposes of gossip.
5. In GRO-B Dad commenced a hepatitis C treatment with Interferon and Reliferon. The treatment made him really unwell. He lost a lot of weight and suffered with haemorrhoids, tiredness, diarrhoea and vomiting.
6. Whilst he was having his treatment, Dad was horrible, grumpy, angry and wouldn't speak to anyone. He became paranoid and scared of offending anyone. He became a totally different person. It was like he was possessed - it was awful.
7. This period of time was so difficult for our family. At one point my younger sister packed her bag and threatened to go and live with her nanny because she hated Daddy so much. She was GRO-B years old at the time.
8. The periods of treatment with Interferon were the hardest times that I can remember Dad suffering. I recall that he would be sleeping in his chair in the living room and out of nowhere he would start screaming the names of me and my GRO-B. I believe he was hallucinating. It was really frightening. Eventually, Dad was told he had tested negative for hepatitis C only for it to come back one month later. This would have been extremely disappointing for him having suffered such horrible side effects from the treatment.
9. During this time, we knew that Dad needed to have a liver transplant otherwise he would not survive. I felt like we were watching him die in front of us. I felt completely helpless. During this period I rebelled a lot, going out with my friends and drinking and smoking. Looking back I probably put my parents through hell. I believe that I was doing this because I wanted attention and support.

10. Finally, Dad had his transplant at GRO-B in GRO-B For me, things were better at school at this point. The staff at the school were sympathetic because of what we were going through at home. However, I found it all to be a bit late and a bit false given the way they had treated us when they thought that Dad had a drinking problem.
11. Around this time I had a very good group of friends at school which provided me with some respite from our very difficult home environment. However, at home there was more trouble with older kids who lived in our area who used to shout abuse at me and knock on our door to antagonise our dad. Everybody in the area knew he was unwell and some malicious youngsters made our lives a misery because of it.
12. My mum always just got on with it. I remember catching her crying once. She had hidden away to try and not to let us see it. It occurred to me that maybe she cried all the time but tried to protect us from it. She didn't really have anyone to talk to about what she was going through and she remained strong and never let it show how much she was suffering.
13. The years after the transplant are hard to describe in words. For the initial period afterwards, while Dad was trying to recover from the surgery, it was touch and go and I would be terrified to go out of the house and leave him in case he died. The affects of this meant that I wouldn't go away on holiday or socialise with any of my friends. I lost contact with a lot of friends through staying at home to make sure that Dad was ok.
14. Dad's health was definitely improved since the transplant. However, he still has a lot of problems. He has extremely limited mobility and suffers from crippling fatigue. What happened to Dad has really affected my trust in the NHS and in hospitals in general.
15. I am so frightened of hospitals now that when my GRO-B recently I almost died because I didn't go to hospital for a week after

the pain had started. As a result I had to have major abdominal surgery. Even though I am told that blood and blood products are now safe, I was terrified when they mentioned the possibility of a blood transfusion following my surgery.

16. When I look into the future, although I love children, and work with children, I am terrified about the prospect of having my own. I carry the haemophilia gene which means there is a risk that my children will inherit haemophilia. In terms of the birth, if anything goes wrong, as a result of my previous surgery, I can't have a normal caesarean section and would have to be cut vertically. I am terrified to go ahead and attempt to have children because of what might happen. I also feel terrified that if I had a haemophiliac son that something like what happened to my dad could happen to him to. I feel angry that my feelings about starting a family are tainted by the horrible experiences that me and my family have endured.

6. Treatment/Care Support

1. I am aware that my dad had to obtain permission from the government for the funding of his last course of treatment for hepatitis C. I don't believe my dad was ever offered any counselling or psychological support. I certainly have never been offered any counselling or psychological support. I feel that I may benefit from this as it is difficult to know what the long term affects are of what we have experienced. I know personally that I no longer have any trust in anyone.
2. I have extreme anxiety but I am afraid to go to the doctors to try and address this. Whilst Dad was ill when I was younger I spent so long in the house that I now find it very difficult to socialise and meet new people. I believe that I would have been a totally different person had my dad not been infected. I recently started a new job which was horrendous and I felt nauseous every single morning due to my anxiety. I hope that this will ease over time but it is important to note the long term and far reaching affects and consequences of Dad's infection.

7. Financial assistance

1. My dad, F will provide information about financial assistance he has received in his witness statement to the Inquiry.
2. I can say that as a family, I recall when Dad stopped working, we all had to cut back on spending. As a child I noticed that we didn't get the same treats from the supermarket anymore and that we went down from two cars to one car as a household. I recall my mum trying to economise by buying 'own brand' cereals instead of the main brand such as coco pops.
3. I remember watching the house get more rundown around us because Mum and Dad could no longer afford to maintain or repair it. Things would take a long time to be fixed or replaced and I remember our birthdays being pulled back and our pocket money going down. To lose the income of the main breadwinner must have been extremely difficult for Mum and Dad when they had such young children.

8. Other Issues

1. I think what happened with the contaminated blood scandal is outrageous. Equally outrageous is the length of time it has taken for victims like my dad to be listened to. I hope that this Inquiry is able to get some answers. The victims need to have some sort of closure and an explanation as to who was responsible for the decision to use contaminated blood. They need a definitive answer as to whether this was a mistake or if it could have been avoided. I really hope that this Inquiry is able to assist the victims and work to reduce the suffering of all of those both infected and affected by contaminated blood.

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Statement of Truth

I believe the facts stated and this witness statement are true.

Signed

GRO-B

GRO-B

Dated... 14.7.19