

ANONYMOUS

Witness Name: **GRO-B**
Statement No: WITN2552001
Dated: 14th February 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 12th December 2018. 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**
GRO-B I live at this address with
my husband **GRO-B: H**

2. I have been asked to write a statement about my husband's infection of HIV and Hepatitis C, which he contracted from a blood transfusion between **GRO-B** In particular, the nature of his illness and how the illness has affected him, the treatment he received and the impact it had on my family and me.

2 How Affected

1. At the age of 6 months [H] was diagnosed with Haemophilia A.
2. On one occasion in or around [GRO-B] when my husband was about 7 years old he had to go to the [GRO-B] because he suffered a bleed. On his way home from the hospital he began to vomit. Once back home, his General Practitioner (GP) [GRO-B] [GRO-B] came to see him and his parents were told that he had contracted Hepatitis B.
3. I remember in [GRO-B] before [H] and I got married he told me he had to have a test for HIV. We knew that this 'new' virus was going around the gay community as it had been on the news. [H] had been invited by [GRO-B] to do some tests for HTLV III. I remember [H] telling me about the consultation he had with [GRO-B] where he said he would be extremely surprised if [H] didn't have the virus considering the amount of treatment he'd had. I think [H] had the result in [H] [GRO-B] which was positive.
4. It wasn't until [GRO-B] when [H] learned he had contracted hepatitis C. He had no symptoms and was told by [GRO-B] during a routine appointment. It appears however that there are medical records missing for the period between [GRO-B] and therefore no definite date of diagnosis.
5. No other family member suffers with Haemophilia.

3 Other infections

1. There is also a possibility [H] may have contracted CJD.

4. Consent

1. I know [H] knew about being tested for HIV but he did not know he'd been tested for hepatitis C, until he received the result.

5. Impact

1. When [H] had his positive results for HTVL III I found out I was pregnant. At the time I couldn't face being tested for HIV so we decided to terminate the pregnancy. We felt it wasn't a priority as [H] would only have about three years left to live. We decided to get married as time wasn't on our side as we were made to understand time was very limited. I was doing my A levels and dramatically failed them. I was very worried about [H] being infected myself and we just wanted to focus on what we had left together. We built our own little castle, ignoring what was going on outside.
2. After having a test for HIV and it was negative we wanted to have children and [GRO-B] referred us to an obstetrician. We were advised the best way to conceive was to have unprotected sex in the window where I was most fertile. I had to take my temperature each day in order to find out when I was ovulating. We now have [GRO-B] lovely children.
3. It was my choice to stay at home and look after [H] and the children. I gave up my job. It was hard and difficult at times and I have been in so many hospital waiting rooms with him.
4. [H] became very inward and I do wonder if he is ever content. He sees his glass as half empty rather than half full and he is used to seeing it that way. He does see some humour in this.

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5. I tend to focus on something else when I feel the past creeping up on me. Recently when I started my nurse training I was in an infection control lecture where the lecturer discussed haemophiliacs getting HIV. After the lecture I went to the toilet and cried. Although it is necessary having to discuss the issues for this Inquiry, it has also taken its toll on us emotionally.
6. We have built up different areas where we can be honest to certain people. It has been recognised by a colleague that I don't open up. I don't think I have always been like that. We certainly have built up walls around ourselves and don't open up to people we don't know.
7. When H was told about contracting HIV through the contaminated blood he was crushed. We thought he would be dead in two years.
8. We have only ever told immediate family members and very close friends. We never let on to anyone else. I remember H told a workmate when he was drunk and it really worried him, that he may tell others as there was a negative reaction from him. He went round to see his workmate the very next morning to ask him not to spread it around and to see if they were still friends.
9. It had a massive impact on any future planning. We were constantly in fear of the future.
10. We never let on to our children as they were growing up. We were too afraid of the stigma that came with it and didn't want them to be bullied. Our son was told when he was GRO-B old because unfortunately he had GRO-B. We told him as we felt we could help him to deal with his illness better if he knew what we were going through or had gone through. I told GRO-B when she was GRO-B years old. She had fallen out with H because he had become preoccupied and was very short with us all. She was very upset about it. Our GRO-B who is

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now [GRO-B] years old has grown up with knowing about it. It's a totally different approach now regarding the stigma.

11. [H] lacked in ambition, lost a lot of confidence and had to give up his job because of joint problems. We couldn't get life or house insurance.

12. It still upsets [H] now, as he was very cold towards the children when they were younger. It was the not knowing if he would be around for them. He feels the father and children relationship was taken away from them.

6. Treatment/Care Support

1. When [H] was diagnosed with HIV there was no information, support or advice. It was only from what I saw in the media that we decided to terminate the pregnancy. We were advised not to have children.

2. When [H] first learned he had contracted hepatitis C he was offered interferon, which he turned down at first, as we knew people who had experienced terrible side effects from it. Eventually he did try it, and it set him back five years. The side effects were horrible, he became depressed and aggressive, He had diarrhoea for a year and his hair started to thin. It was a horrible time for him and our family. It didn't work. [H] applied for another new treatment and was turned down. He knew his liver was scarring and he was desperate. One day, out of the blue the Pharmacist from Virology at [GRO-B] phoned him about a new trial. [H] tried this and it cleared the virus.

3. It took about six years before [H] saw a Virologist and to find out how far the HIV virus had progressed. We were always worried as we didn't know what was happening. He now sees [GRO-B] [GRO-B] on a regular basis. [H] is now being medicated with Tryamac for HIV, it does make him feel sick for a few hours after taking it but it keeps the virus under control.

4. We joined patient support groups and it was through these we managed to get a large proportion of information. We were able to access support and counselling and advice, family days out and support for the children. Victims of this terrible scandal set up the GRO-B The hospital signposted us to it.

7. Financial assistance

1. H received compensation of £60,000 through the Macfarlane Trust from the government and had to sign a declaration so he couldn't sue for any other infections.
2. H received £20,000 Stage 1 award from the Skipton Fund and he also gets a yearly award of £18,000.
3. H took out litigation in the USA and got a one off payment of £20,000.
4. Members of the GRO-B and McFarlane Trust did all applications and it was a great support for us all.

8. Other Issues

1. I do feel H should be compensated for what happened to him. We have had to jump through so many hoops to get awards and I believe we could have accessed a lot more financial assistance if bureaucracy of forms was easier. For example, for adaptations to the house, we needed to prove it needed to be done, get social worker's reports, three quotes before it goes to a board. You can't guarantee you will get help after doing all of this work.

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Statement of Truth

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

Signed

GRO-B

Dated 14.2.19