

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN2261001

Exhibits: **None**

Dated: 30th November 2018

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 the 30th November 2018.

I, **GRO-B**, will say as follows: -

Section 1. Introduction

1. My name is **GRO-B**. My date of birth is the **GRO-B** 1947. My address is known to the Inquiry. I am retired now, previously I worked in the health service, as a **GRO-B**. **GRO-B**. I worked in this role for 16 years. **GRO-B**. **GRO-B**. **GRO-B**. I intend to speak about my brother, **GRO-B: B**, who had hepatitis C which resulted in hepatocellular carcinoma, which killed him. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together as a family.

Section 2. How Affected

ANONYMOUS

2. [B] was a very healthy person. He received a blood transfusion in 1986, for a perforated ulcer which required an operation. During this operation, he required to have a blood transfusion. He was healthy for many years after this and then in 2010 he was diagnosed with cancer and simultaneously told that he had hepatitis C. This information was in his medical records for many years, but no one bothered to tell him. He then went on to have treatment for his cancer but was unable to ever recover to a point where it would have been appropriate to receive treatment for hepatitis C. He passed away in [GRO-B] 2013.
2. [B] didn't have a prior condition. He was very healthy, he had the blood transfusion in 1986.
3. [B] received a blood transfusion during an operation for a perforated ulcer. I don't know how much blood he received. My sister in law [GRO-B] [GRO-B] will know this information.
4. [B] was under the care of the Edinburgh Western General Hospital for his cancer in 2010 until his death. He received the blood transfusion at [GRO-B] in 1986. He went to one appointment at the Edinburgh Royal infirmary in regards to the hepatitis C and was never seen again. He was registered with [GRO-B]; I do not know the name of his GP.
5. [B] received the infected blood in 1986 when he had the transfusion. I cannot recall when this took place exactly, I just remember it was around the summer time. I would like to set out to the Inquiry that I would like the following question addressed. The information that [B] had hepatitis C, lay in [B]'s medical records for many years. This was never addressed and he was never told about this until 2010. Why was he not informed? They must have tested him; hepatitis C doesn't just show up in a routine blood test. I know this because I worked in the medical profession.

ANONYMOUS

6. After he was released from hospital in 1986 [B]'s recovery was unremarkable. He was a fit and active person and from 1986 until 2010, he played golf, he ran a successful business and he was a happy go lucky person, full of life. Then in 2010, he started complaining of back pain. He went to his GP and they decided that he needed a new hip, which turned out to be a load of nonsense. [B]'s GP was a nightmare and did not listen to [B]. [B] was telling this GP that he had lost a lot of weight in a short period of time, around one and a half stone and the GP still did not do anything to prompt further investigations. He was referred to hospital, for a scan in relation to this new hip and while he was waiting for this to occur he attended physiotherapy. The physiotherapist had concerns as [B] had numbness down one side of his body by this point. She told him to go to Accident and Emergency which he did at the Western General Hospital. They investigated further and in the summer of 2010 he was told he had a tumour. I remember that day because [GRO-B] phoned me in a state telling me about this. I cannot recall details of the conversation now, just that it was very upsetting. The hospital did further investigations and several weeks later, [B] was told that he had stage 4 non-Hodgkin's lymphoma. Simultaneously, he was told that he had hepatitis C and that this would complicate his cancer treatment. The consultant then made the throw-away comment that [GRO-B] also may have been infected. That information right there, very nearly killed [B]. The consultant told them to go home and come back on Monday to start chemotherapy to allow them time to absorb things. On the Monday, [B] went back to the Western General for chemotherapy and [GRO-B] had to go to her GP to be tested. [GRO-B] tested negative and her results came back about 5 or 6 weeks later. [B] and [GRO-B] went through the first 2 months of chemotherapy treatment with this extra dark cloud hanging over them. [B] couldn't stand the idea that he may have infected [GRO-B] and it was an incredible relief to him that she did not become infected.
7. The Oncologist provided the information at the Western General Hospital when they were talking to [B] about the cancer. They just said

ANONYMOUS

that the hepatitis C would impact on the treatment for the cancer, further information was very limited. They took 20 years to inform him that he had this. I remember afterwards that GRO-B went to investigate if she could take matters to court and proceed with a civil case, to be told that the case had become time-barred, even though they didn't tell him about his diagnosis. It was appalling.

8. There was nothing they could do at the stage they told him. The focus had to be on the cancer, they couldn't focus on the hepatitis C. The doctors said that they thought he would be ok. They said that he could have a liver transplant in the years to come if required. I'm not sure which consultant gave the information to B about the possible future liver transplant, the hepatitis C and the cancer. It is very difficult for me to remember the details of this. I was very ill after B died and this has had an impact on my memory.
9. The information should have been provided to B in 1986. This would have given him the opportunity to seek treatment.
10. The situation was very difficult. What else could the doctors do at that point other than tell the truth. They didn't continue to bury it at that point.
11. The information that B got about this was that he may have infected GRO-B as well. GRO-B was totally devastated by the whole thing; B was upset, not for himself, but for GRO-B. He was devastated at the idea that she may have been infected as well.

Section 3. Other Infections

12. I am not aware of any infection that B received other than hepatitis C.

Section 4. Consent

ANONYMOUS

13. Yes he was not made aware, he was not told he was being tested for hepatitis C in 1986, but the information is in his records. No one even tried to tell him.
14. Yes he was tested without his consent for the same reason as I describe in a.
15. There was no information about the hepatitis C until 2010, so no he was not given adequate information.
16. Yes I think they were testing him for research. They were fully aware in 1986 that he had this. Because of my professional background I am aware that hepatitis C is not a standard test that is routinely done. They were investigating matters without his consent and then they just left him for over two decades. We have never received an explanation as to why this has occurred, no awareness at all and I would like this addressed by the Inquiry. He was robbed of the opportunity to get well and ultimately it did kill him.

Section 5. Impact

17. It is difficult to answer this question because [B] was really ill with cancer. He felt sick constantly and off-colour, he was losing weight and when he did undergo the intensive chemotherapy treatment this may have activated the hepatitis C. Most of the symptoms he experienced however, were related to the cancer.
18. The cancer. From the summer of 2010, [B] was then undergoing chemotherapy which was very intensive. He was in and out of intensive care constantly, the doctors didn't think he was going to pull through. It was stage 4 non-Hodgkin's lymphoma after all, but the primary source of his cancer was his liver. This had spread to his back. The liver cancer had come from the hepatitis C. From the summer of 2010 to December 2010 [B] was only allowed home for two nights. He was constantly ill

ANONYMOUS

and at one point he had to be put in an induced coma because he was suffering so much. Ultimately, the cancer became inactive, it did not go into remission but it stopped growing. I cannot recall when the cancer was declared inactive exactly.

19. [B] went for a routine scan in October 2012 to check how he was, by December there were no results and he started to feel unwell. [GRO-B] contacted the hospital to try and get an earlier appointment for [B], but was told that they were too busy given the time of year. The consultants were too busy to see [B] which I think is disgraceful. You do not say that to a cancer patient when they have concerns. By the time January rolled around, [B] was so unwell that [GRO-B] took him to Dumfries Royal infirmary. Dumfries contacted the Western General Hospital and requested the scan results be sent over immediately. The Western General did this over their computer network. The doctor at Dumfries Accident and Emergency then told [B] that the cancer was back and it was now terminal. He was only expected to live for a few more weeks from this point. There was no explanation as to why the results had been sitting there for a long time, why he was not notified that he was at death's door. It was a total lack of care. The Western General Hospital, did apologise for this behaviour and said they would investigate but nothing ever came from this. The consultant [GRO-B] and [B] spoke to at the Western General, after this terminal diagnosis, did say that it was too late for treatment and that, had the scan been picked up earlier, as it should have been, then they could have treated it. [B] died a few weeks later in February 2013.
20. [B] never had treatment for the hepatitis C because his platelet levels never rose high enough. The doctors were hoping that he would recover from the cancer treatment to a level that would allow them to tackle the hepatitis C but this was never the case.
21. [B] wasn't told about his diagnosis, so that was the ultimate obstacle he faced.

ANONYMOUS

22. There was a treatment available for the cancer in January 2013, but the side-effects looked incredibly brutal and we would have had to have paid for it. We were told it was too late at that stage and it would make no impact on [B]'s cancer. We would have done anything to save [B], he was not given the opportunity to save himself all the way through. We would have been willing to purchase drugs from the United States but the doctors would not allow us. They said it was too late. He literally wasted away in front of our eyes.
23. There were no mental and physical effects from the treatments for hepatitis C as he never received treatment. For the cancer, this was a very intensive treatment. Typically, when you have cancer you have one session of chemotherapy every three weeks. This is to allow time for your body to recover as the treatment makes you incredibly unwell, because [B]'s cancer was at stage 4, aggressive treatment was needed and he received continual treatment over a core four-month period. He went into an induced coma because of the pain and had to be admitted into intensive care. He did pull through the treatment, he was always a fighter and would be the best he could be.
24. No I don't think his infected status impacted upon any other medical care.
25. [B] had a very active social life, obviously that stopped when the cancer emerged, he had a lot of friends very close loyal friends that socialised with him and [GRO-B]. Now [GRO-B] is on her own. They used to be a couple, now she is half of a couple and she is on her own. There used to be a whole group of them, they would go out for the weekends and for dinners and go cruising every year. She no longer participates in this anymore. Her friends keep inviting her but she feels that she is one half now and it doesn't feel right. [GRO-B] and [B] were together from the time they were teenagers. They worked together all their lives, they ran a business a very successful business and lived together. Now this

is all gone. She had a very good standard of living that is all gone, it has all been taken from her. The last week of his life [B] went home, but then collapsed a few days later, he was then admitted back into hospital and that is where he remained. When I came to see him, his sight was gone but he could still speak to us. Those last days of his life I remember very well. He had a steady stream of visitors from 6 in the morning to night time from people wanting to say goodbye, from teenagers to older men and women in their 70s. He was well loved.

26. It must have been a very lonely place for him, it's very difficult to describe because I've been there myself. I have had cancer and I can understand the fear. I was diagnosed with cancer in 2006 and went into remission. After [B] died, I thought that my cancer had re-occurred due to physical symptoms I was experiencing, but it ended up being a combination of an infection and stress.
27. It is difficult to answer this question about stigma, because a lot of people don't understand hepatitis C. For [B] his friends and family understood him and there was never a problem. But the general consensus was that it was gay people or drug users that got it.
28. [B] lost his business as a result of his illness. This is something I don't wish to participate in or discuss. I think this is something [GRO-B] can discuss if she wishes.
29. After [B] died, I became ill and was off work for several months. I couldn't concentrate before he passed away and after he passed away it was very difficult. I realised I couldn't continue working after he passed on. My employer made an organisational restructuring decision and based on that, I made the decision to stop. I retired in March 2018. At this point I was a manager.

Section 6. Treatment/Care/Support

ANONYMOUS

30. [GRO-B] looked after him, the [GRO-D] nurses came once but their service was not good. I was disappointed in that, they only turned up once and another time, when they didn't turn up at all. They were not available. The backup support was not there, it didn't exist.
31. No psychological support has ever been made available to myself, to [B] when he was alive or to [GRO-B]. This is not adequate. [GRO-B] was left in a very isolated situation, she had a close contact with Haemophilia Scotland with [GRO-B] and he helped her quite a lot. He spoke with her, which is something she really needed. He understood because he has met a lot of people who have experienced similar problems. For myself, yes it would have helped me as well.

Section 7. Financial Assistance

32. I know he did get something from the Caxton Trust but I've never discussed details of this with [GRO-B] so I don't know.
32. [GRO-B] will know the answer to this I don't know the information.
33. I don't know about the process of applying for financial assistance.
34. I don't know if any difficulties and obstacles were faced when applying for financial assistance, from my perspective things seem to happen quite quickly.
35. I'm not aware of if there were any preconditions imposed.

Section 8. Other Issues

36. I have no other documents to provide to the Inquiry.

ANONYMOUS

Statement of Truth

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

Signed

GRO-B

Dated

24 FEB 2019