

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN2183001

Exhibits: None

Dated: 28th May 2020

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 15th May 2020.

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

Section 1. Introduction

1. My name is **GRO-B**. My date of birth is **GRO-B** 1945 and my address is known to the inquiry. I am currently retired but I previously worked as **GRO-B**. I married my husband **GRO-B** **GRO-B**. I intend to speak about my son **GRO-B: S** who was born on the **GRO-B** 1971 and was infected with hepatitis C after receiving blood products to treat his haemophilia. I will speak in particular about the nature of his illness, how the illness affected him, the treatment he received and the impact it had on his and our lives together as a family.
2. I wish to remain anonymous for this statement for privacy reasons. My son **GRO-B: S2** has provided his own statement to the Inquiry, therefore I will focus this statement on my other son **S**.

Section 2. How Infected

3. [S] is a very caring, family orientated person. He is married and has [GRO-B] children of his own now. [S] has always been quite a sporty person and he is a keen cyclist. [GRO-B]
[GRO-B]
4. [S] has haemophilia A. He received cryoprecipitate to treat his haemophilia at [GRO-B] Hospital, Glasgow until he was sixteen years old. At sixteen years old he was moved to the Haemophilia Centre at the Glasgow Royal Infirmary, where he started receiving Factor VIII. I cannot remember the name of his consultant at [GRO-B] but it was Professor Lowe in charge of his care at the Glasgow Royal Infirmary.
5. I cannot say for certain when [S] was infected but it could have been any time after he started receiving Factor VIII when he turned sixteen.
6. No information was ever provided to either [S] or myself about the risk of infection from receiving these blood products. If he had a bleed, he would get treated. No one ever mentioned there being a risk of anything.
7. I cannot remember exactly when [S] was diagnosed, but I remember it was around three or four years after he had been transferred to the Glasgow Royal Infirmary. One of the times I had taken [S] to the Haemophilia Unit, we were pulled to the side and told that they had found something in [S] blood work. It was Professor Lowe that spoke to us and he told us that [S] had contracted non-A non-B hepatitis. The crisis around hepatitis had not happened yet so at that time it did not seem like something to worry about in terms of the way they told us about the infection. In hindsight, they downplayed it quite a bit.
8. I cannot remember specifically what we were told about the infection on that day. What I can say is that it was very concerning to hear as [S] mother but Professor Lowe made it sound as if there was nothing to worry about.

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9. I think the information we were given was not enough for either of us to understand the situation. It was not made clear at the time that the infection could get worse or could lead to complications further down the line. It felt like Professor Lowe glossed over a lot of things.
10. It's hard to say whether [S] could have been told about his infection earlier than he was. When he was given the diagnosis, they don't tell you how long you have had it or when they think you might have contracted it. All they said at [S] diagnosis was that he had contracted the infection, they did not give us any information about the state of things before that point.
11. All I can say about how we were told about [S] infection was that the way it was put to us, it was not something we should be worrying about. They didn't seem to think it was that big a deal, which looking back was completely wrong. They didn't say anything about continuing to monitor [S] or anything like that. We pretty much heard nothing more about it until [S] was offered Interferon in his twenties.
12. At [S] diagnosis there was no information provided about the risk of cross infection. That was something he was told later on but we didn't receive any information about that kind of thing initially.

Section 3. Other Infections

13. I do not believe that [S] contracted any other infections other than hepatitis C from the blood products he received.

Section 4. Consent

14. I think [S] probably was treated or tested without his knowledge or consent. At the Haemophilia Unit, he was never told that he was going to be tested for anything specific, just that were going to do some blood tests. That

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was something they routinely said to him when they would take blood from him. He wasn't told about being tested for hepatitis but they must have performed that test at some stage before his diagnosis.

15. [S] could have been tested for research at one stage. I remember once when he was in his late teens he was being tested for something to do with research but I cannot remember exactly what it was.

Section 5. Impact

16. [S] infection affected his confidence a bit, I remember he didn't go out and socialise as much as he used to. I feel it restricted him a bit psychologically, he did not tell anyone about his infection. The stigma around his infection was something he worried about a lot. People didn't understand a lot about it in the past, they would try and avoid touching you or things like that. It was something he dealt with a lot on his own and I know that must have had an effect on him mentally. I think being young helped [S] handle things a bit better, he was still at home at the time so he had support from us and were always there to help him if he needed.
17. [S] received treatment a few years after his diagnosis and the treatment was successful, so thankfully he didn't have to deal with any of the physical effects the infection can cause for some people.
18. [S] did not develop any further medical conditions or complications as a result of the infection.
19. At the start of [S] infection, we were given the impression that it was nothing to worry about. As hepatitis C became more and more known about, it was something that worried us all quite a lot. We thought that worry would fade somewhat when [S] began his treatment a few years later, but the treatment itself was an extremely traumatic experience for [S]. For over a year during the treatment I could see that he was having mood swings, he

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was fatigued and it was causing him a lot of pain emotionally. When he was finally cleared and he was told the treatment was successful, it was a huge weight off his shoulders. After his treatment he moved [GRO-B]

[GRO-B]

, and lived there for a time

[GRO-B]

[GRO-B]

20. [S] received Interferon and Ribavirin to treat his infection, he was actually one of the first four people at the Glasgow Royal Infirmary to receive that combination. I cannot remember exactly when [S] began this treatment but it was when he was around twenty or twenty one, it was still Professor Lowe in charge of him at that time. The treatment lasted around a year and [S] was given the all clear once he had completed the treatment.
21. [S] did not face any difficulties or obstacles in accessing treatments. He was offered Interferon and Ribavirin as soon as it was available and the treatment was successful.
22. [S] first treatment was successful so there was no need to consider any other treatments. I do not think there were any other treatments he could have received before Interferon and Ribavirin became available.
23. The treatment was very difficult for [S]. It would make him feel very low mentally. He would sometimes be quite short tempered and would have a lot mood swings. I think the side effects of the treatment were essentially all mental for [S] he didn't really suffer from any physical symptoms other than some fatigue.
24. The only effect that [S] infection had on his treatment for anything else was that he used to have to explain his infection whenever he saw someone new, either at the hospital or the dentist. A lot of people did not know a lot about the infection in those days. Things like that are in your records now and that means he doesn't have to keep explaining the past every time, but he used to have to do that a lot.

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25. I think the biggest impact the infection had on [S] was when he was getting married. It was a big decision to have to explain to his now wife what the infection meant and what it all would involve for her. They both knew that the infection could be spread through bodily fluids so they just had to be very careful. They had to take that chance if they wanted to have a family. I know telling her all that cannot have been easy.
26. For the family, hearing about [S] infection was absolutely devastating. To hear that he had this infection and that there was no cure for it was very distressing. We had to make sure that no one outside of the family knew about it because when [S] was first diagnosed people didn't know what it was. If we kept to ourselves it meant that we could avoid a lot of the stigma that was associated with the infection in those days. Even today, there are some people close to me who might know that my sons are haemophiliacs but nobody knows about the hepatitis C.
27. Even thinking back on [S] infection now, it's still very painful. Haemophilia is passed on through the mother and I sometimes think to myself, you've caused this. There's a lot of guilt there because I gave him haemophilia and these were the consequences of that. It's very upsetting to think about. The infection was just a very worrying time with [S] and it still is to some extent because my other son [S2] was only treated for his hepatitis C in the last few years.
28. As a family, we kept [S] infection to ourselves and so we didn't really face any stigma relating to it. Obviously there was the worry that people might find out but we didn't face any stigma from anyone directly.
29. [S] infection did not affect his work really. He had one instance many years ago where he had to leave a job because of his haemophilia that went to a tribunal, but after that he didn't really have any issues. He worked for a company in [GRO-B] and then he moved to another company in [GRO-B]. Not long after he had started the job in [GRO-B] [GRO-B] he started his family and decided to become self-employed

because it was easier to work from home. Being self-employed meant that he didn't have the same worries that some people have around getting time off or anything like that. I don't think [S] infection had any major financial effect on him either.

Section 6. Treatment, Care and Support

30. As far as I am aware [S] did not face any difficulties in receiving treatment care or support because of his infection.
31. No psychological support or counselling was ever offered to [S] or myself because of his infection. I think that is something that we all would have probably benefited from at the time, but nothing was offered.

Section 7. Financial Assistance

32. I know that [S] received a payment from the Skipton Fund. It was the payment they made to all haemophiliacs, I don't think it was in relation to his hepatitis C. I could not say how much he received or when he received it, [S] is a grown man now so I'm not always privy to that sort of information. [GRO-B]
[GRO-B]
[GRO-B] so I heard about the Skipton Fund. [GRO-B]
[GRO-B] and told [S] about it. I couldn't really speak on what the application process was like for him because that was something he did himself.
33. [S] also received a payment from the SIBSS in relation to his haemophilia but again I could not say how much he received or when the payment was made. As with the Skipton Fund, I found out about SIBSS through my work with the haemophilia organisations I am a part of and told [S] he should apply. I think that was around five years ago. I cannot remember what the application process for that fund was like, [S] didn't mention anything to me, so I assume there weren't any problems.

34. I feel that one thing the current payments do not consider is the cost of insurance for those that have been infected. The payments for insurance can be very high if you have something like hepatitis C. It can be difficult to even get insurance in the first place for some people. Even when my boys were very young, because of their haemophilia, I could be paying double the normal premium. That kind of issue happens a lot for people with hepatitis C. I think something should be done to help those affected by this with their insurance because insurance companies treat people with hepatitis C like pariahs. Giving out the payments is all very well but there are other things the funds could be helping people with.

Section 8. Other Issues

35. I think the NHS should have been much more open about what was happening from the beginning. It felt like a closed shop right from the start, no one knew what was going on and there was no information out there. There was nobody willing to take any responsibility for what had happened and that's not right.

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Statement of Truth

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

Signed

GRO-B

Dated

3rd AUGUST 2020