

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN2120001

Exhibits: WITN2120002-008

Dated: 13th 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 9th 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 1943. My address is known to the Inquiry. I am currently living in the GRO-B GRO-B I intend to speak about my late husband GRO-B: H and his infection of hepatitis C. 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. H and I were married for over GRO-B and have one son GRO-B

Section 2. How Affected

2. My husband was admitted to the Queen Elizabeth Hospital in February 2019 after he suffered a brain haemorrhage. He was eventually transferred to [GRO-B] on the 8th April 2019. He remained there until his death on the [GRO-B] 2019. I make this statement [GRO-B] since he died so everything is very raw. For the past five months I have visited [H] every day and stayed with him for hours at a time. Now that he has gone I am lost and don't quite know what to do with myself.

3. [H] was diagnosed with Haemophilia, type A in early childhood. I do not know when he was diagnosed exactly. This information will be contained in his medical records, however I note from a letter in [H] hospital records that some medical records are missing. I produce this letter in evidence and identify it as **WITN2120002**. The severity of his condition was considered mild.

4. I am not aware of the names of the blood products that [H] had received because of the long history that [H] had had receiving blood products from a young age. In the early days he had "venomous treatment", I do not know how long for. He told me his treatment was moved onto blood product treatment, I do not know when and eventually I believe he was moved onto Factor VIII. [H] told me that he was on this treatment from 1973. I am aware that [H] did receive Factor VIII but I am unaware of each occasion.

5. [H] told me he attended the Royal Infirmary hospital in Glasgow as a child, it was known as the Old Glasgow Royal. He has told me that he had attended the Edinburgh Royal Infirmary historically. I do not know details of the doctors involved in prescribing the products to him, this is information that will be in [H] medical records. [H] did not divulge details of his medical history to me. It is only recently that he started to tell me some details.

6. The dates that [H] received the infected blood products are unknown to me. This will be information contained in this medical records.

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7. There is a letter in [H] hospital records that suggests [H] was told that he had hepatitis C on the 20th August, 1991. I produce a copy of this letter in evidence and refer to it as **WITN2120003**. He did not tell me he was infected and I only found out in the late 1970's when the Scottish Blood Transfusion Service told me I was not able to donate blood because of [H] infected status. It would seem that they knew he was infected in the late seventies but did not make [H] aware until 1991. This made me feel very bitter towards [H] at the time because I believed he would have known he had hepatitis but in hind sight he might not have been given this information. I did not raise it with him afterwards as our marriage has not been in a good place for many years. From a letter dated 8th May, 1990 from Doctor Lowe in [H] hospital records it would seem he is recorded to have a degree of chronic non A non B hepatitis in 1983. This is hepatitis C but it was called non A and non B at that time. Doctor Lowe says in the letter that it was common for haemophiliacs treated in the past with blood products to have non A and non B hepatitis. I produce a copy of this letter in evidence and refer to it as **WITN2120004**.
8. [H] told me that in the early days when he received the blood products, he stated that there were no details or information provided to him about hepatitis C.
9. Adequate information was not provided to understand and manage the infection to my knowledge. This is what [H] had told me but he did not explain why.
10. I do believe that information about [H] infection was provided to him. [H] was informed about the infection in 1991. He did say that he had some blood tests done and that he tested positive for non A, non B hepatitis in 1978. This is information he has told me. He says he was given this information in 1991, as it was contained in his medical records.
11. I don't know if I have views about how the results were communicated to him

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because [H] did not tell me. [H] provided me with no information or view about how he felt about this.

12. I don't know what information was provided to [H] about the risk of spreading the infection, he never mentioned any risks to me and indeed did not even tell me he was infected for all these years.

Section 3. Other Infections

13. I have no knowledge or information about any other infection that [H] has contracted as a result of the infection. I do remember conversations he had with other haemophiliacs, who had been infected, on the phone where he talked about vCJD but he didn't speak to me about that. I note there is mention in his hospital records relating to a hospital admission of vCJD. I produce this record in evidence and refer to it as **WITN2120005**.

Section 4. Consent

14. I believe that [H] was tested without his knowledge. The information that he was infected was in his medical records and he was not aware he had been tested for hepatitis until 1991. There is evidence in [H] hospital records that he was also tested for HIV I do not believe [H] knew he was being tested for that. I produce medical entries in evidence and refer to them as **WITN2120005** and **WITN2120006**.
15. I believe that [H] was tested without his consent. Again the information was in his medical records and it follows that if he was not told the test was being conducted, he was not giving consent.
16. I believe that [H] was tested and treated without being given adequate or full information as the information was in his records but he was not advised of this for many years as far as I am aware. I found out what hepatitis was

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through my work as a midwife and [H] found out through information available in the media.

16. I cannot say if [H] had been tested or treated for the purposes of research.

Section 5. Impact

17. I think it is difficult to really put into words the physical and mental effects of [H] being infected. As we were given no information about the infection it is difficult to understand how he felt. I am aware that he was not happy about the results as well as not being told they were testing him for this. The physical effects for [H] were tiredness and feeling the cold. Whether it was warm or cold he always felt the cold. The heating in the house was on 24 hours a day. From an employment perspective when he was working for [GRO-B] Glasgow, I remember one occasion someone being asked to go somewhere in Scotland and he could not be considered because of his health status. [GRO-B] My view is that [H] attitude towards me had changed, it just got progressively more extreme over the years. He spoke at me rather than to me. He was personally abusive to me. This became more noticeable over the years before he died. He was doing this from the 1990s. I do think there are underlying mental health issues or maybe slight depression. He may have discussed this with his GP, but he does not go into detail with me. I do feel he was taking out his mental health issues on me though.

18. I am aware of tiredness as a further medical condition from infection. [H] complained of tiredness, over the years which started in the early 1990s. It is difficult to say what it was related to though. The tiredness became more frequent but it did fluctuate. He had no issues with things like his liver.

19. Over time, the course of his illness has predominately been dominated with tiredness. I think as the tiredness increased and the feeling of the cold increased, he was finding things harder. I can't make judgements on his physical ability, he was able to walk, but he was unable to walk far.

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20. [H] had no treatment for hepatitis C but he was offered treatment. He did not accept the offer. I don't know why, he showed me a letter that he was offered treatment on the 21 June 2015 from the consultant Ewan Forrest at Glasgow Royal Infirmary, offering him treatment of Harvoni, which is a combination treatment of two medicines called Sofosbuvir and Ledipasvir. [H] has stated he would not go and get treatment and I could not understand why he made that decision.
21. I am unaware of any difficulties or obstacles that [H] has faced in accessing treatment historically, as he refused treatment as recently as 2015. There is a letter in [H] medical notes dated 16th November 1995 that shows he was offered the treatment and was a good candidate for the Interferon. I know he didn't have the treatment but I have no idea why. I assume he refused it. There is a letter in his hospital notes saying [H] was not anxious for the treatment. I produce these letters in evidence and refer to them respectively as **WITN2120007** and **WITN2120008**.
22. I am unaware if there are treatments which I consider ought to have been but were not made available to [H]
23. There were no mental and physical effects of treatment for [H] as he refused treatment for reasons that are unknown to me.
24. There are a few matters that I am aware of in regards to treatment for other conditions with [H] As far as I am aware, if he required treatment at hospital for anything, he was treated as an infected person. He was isolated and if surgery was required, he was the last person on the list for the day, so the operating theatre can be cleaned and disinfected afterwards. I was a midwife in the 1990's, therefore this regime is familiar to me. I consider it unfair to make any comment about this regime at any hospital, because I recognise these rules and why they are in place.
25. I don't think hepatitis C has had a significant negative impact on our life. There

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is a degree of stigma around infection, however that didn't really create a problem for us. Our friends and family have been supportive. We could describe factually what was occurring for [H] to other people when necessary and people seemed to accept this.

26. [H] had early retirement due to organisational restructuring when he was 59, when he retired. Following that, he really made a point of being involved with committees and organisations which became his full time job and kept him occupied. He didn't have a hobby, he didn't like sport because of the Haemophilia, so this is what he took his time up doing.
27. We have one son he was born in 1982. From this point of view, our son could not play sport with [H] This was probably not nice for either of them. I don't think it affected my son otherwise though. [H] became aware he was infected when my son was aged 9. My son did not understand what hepatitis was and he doesn't ask about it now. This does not mean he has not asked his dad however.
28. [H] was rarely off sick from work. He certainly wasn't off for any lengthy spells. He took early retirement in 1995 but this was not related to hepatitis C. He worked in social work and his retirement was due to organisational restructuring.
29. [H] probably could not have got a mortgage on his own. The house is in both of our names. There are things like home insurance and holiday insurance that has always required me to apply. The premiums are a lot higher because he was infected. We had joint bank accounts and there was always a pressure on me to be in employment because there was no guarantee with a haemophiliac that he was going to be able to work continually. I took early retirement as well due to organisational change in the NHS. [GRO-B] My employment came to an end on the [GRO-B] 1995 when I was made redundant, just months before [H] [H] was made redundant at the end of [GRO-B] 1995. I have not returned to [GRO-B] as a condition of my redundancy package was that I did not return

GRO-B for personal reasons.

Section 6. Treatment/Care/Support

30. I have had no involvement in H care historically. What I do recall is that when I attempted to donate blood in the late 1970's, the blood transfusion service said they couldn't take blood from me because of my husband's health. On reflection, the blood transfusion service knew something I did not know about my husband's health. That is how I found out that he had had hepatitis C. He had never had the decency to tell me he had been diagnosed with this. I have a degree of bitterness about this. He never explained to me why he chose not to tell me. H never required assistance with his care and support in consequence of being infected, he was always able to manage himself. I am unaware if H asked for psychological support but I do wonder if this would have been something that he would have benefited from.

Section 7. Financial Assistance

31. H heard about the financial assistance through his membership of Haemophilia Society and GRO-B GRO-B
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32. H received a one off payment from the Skipton Fund in December 2016 in the sum of £30,000.

33. I am not aware on what the process is of applying for financial assistance.

34. I am not aware of any difficulties or obstacles in applying for financial assistance.

35. I am not aware of any preconditions imposed upon H in making an application for support.

36. I have no observations to make about the trusts and funds available.

Section 8. Other Issues

37.

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Statement of Truth

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

Signed

GRO-B

Dated 26th August 2019