

Witness Name: Statement No.: **WITN2289001**

Exhibits:

Dated: 19<sup>th</sup> December 2018**INFECTED BLOOD INQUIRY**

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**FIRST WRITTEN STATEMENT OF** 

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19<sup>th</sup> December 2018.

I,  will say as follows: -

**Section 1. Introduction**

1. My name is  My date of birth is the  1986. My address is known to the Inquiry. I am living with my partner and our 5-year-old son. I am currently a student  based at Glasgow Caledonian University. I intend to speak about my father  's infection of hepatitis C. In particular, the nature of if his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together as a family up until his death.

**Infected Blood Inquiry**

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## Section 2. How Affected

2. Dad suffered from haemophilia, he was infected with hepatitis C after receiving infected blood products, he was diagnosed when I was a young child. This then became a dominant feature in his life up until his death in 2010.
3. Dad had haemophilia, I don't know what type. He was considered mild. I am unsure when he was originally diagnosed. He knew by the time he was an adult, but I am unsure when his family had the diagnosis confirmed.
4. Dad received Factor VIII. He may have also received cryoprecipitate, but I am unsure on this
5. Dad was treated at the Royal Infirmary Glasgow throughout his adult life. I know that he also received treatment at Yorkhill Children's Hospital, Glasgow when he was a child. I wouldn't be able to say the dates though. Dad was registered with GRO-B GRO-B Glasgow.
6. I don't know what dates he received the infected products. My mum, GRO-B will know this information.
7. I am told that when Dad was younger, he was in a fight with another boy and burst his nose. That was when he first received Factor VIII. That is something I remember my mum telling me about, but I could be getting this wrong. He was about 15 or 16 years old when this happened. Dad was born in 1964.
8. I am not aware of any conversations about the risk of being exposed to infection before or after receiving his treatment.
9. I don't know when Dad was diagnosed with hepatitis C throughout my childhood I cannot remember a time I became aware that he had this.

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I have been trying to sit back and think about when I did become aware he was infected, I just can't remember, I don't even know if I knew what hepatitis was. The only thing I can remember is Mum saying Dad has something wrong with his blood so be careful with razors in the house and things. Dad's stuff was kept out of the way but never ever did we know, it was because of hepatitis. But growing up, we wouldn't know what hepatitis was, it was mainly kept secret.

10. I don't know what information Dad received about the infection, from what Mum tells me, there was no information.
11. Adequate information was not provided to Dad, not to my knowledge after conversations with Mum.
12. Information about the infection should have been provided to Dad straight away. There was no purpose in delays.
13. As far as we can see in Dad's notes, Dad wasn't told when he was infected for a long time so he should have been told sooner and should have been given help earlier. Mum has Dad's medical records.
14. When he did find out he was infected he wasn't told anything, maybe advice about spreading the infection came about later on at the Royal Infirmary Glasgow, I don't know anything for sure about this though.

### **Section 3. Other Infections**

15. I am not aware of anything other infections.

### **Section 4. Consent**

16. Yes, based on the medical records which shows he was diagnosed with hepatitis for a long period before he was told.

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17. Yes, further to above, if he didn't have the knowledge about the tests, he wasn't providing his consent.
18. Yes, again, he was given no information when he was diagnosed and full information was in his records and he was not told about this denying him early options.
19. I have only looked at little parts of Dad's medical records, but from what Mum has worked out it just looks like yes that may have occurred. We are also led to the belief that because Dad was considered a mild haemophilic, his body could have recovered without receiving the Factor VIII.

### Section 5. Impact

19. For Dad, there was no physical symptoms for him until he started the treatment to get rid of the hepatitis. The mental impact was the biggest issue, again especially when he was going through treatment and when it didn't work it destroyed him. He became a recluse, spent most of his time in his room. I don't know if he was diagnosed with depression, but I feel like he was. There is a discussion in his medical notes but I don't know for certain if this occurred. I would be surprised if he hadn't been though.
20. The main thing I am aware of was the depression, he turned to alcohol as well after the 2<sup>nd</sup> treatment failed.
21. When he started treatment, everything nosedived. He was drinking a lot; his depression was terrible. I was 16 years old so it is hard to remember. It was only a few years later that Mum and Dad split up because of it all, I was about 18 or 19 when they split. It left me feeling devastated, they had been together for 25 years. Dad moved out and moved to GRO-B where he grew up, so he moved in with his Dad, who he lived with until he died in 2010. I don't know what happened with the hepatitis over time, I was only aware of the alcohol because I think all

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treatment with the hepatitis was abandoned because of the alcohol; he wasn't going to liver scans or anything, so I don't know. In 2010, I got an unexpected phone call from the Royal Infirmary Glasgow and when we arrived at the hospital, they told us that they believed that he had had a brain haemorrhage. It was quite sudden and was admitted to Intensive Care, a couple of weeks later he passed away. We expected him to pass away quickly, but he didn't it took several weeks.

22. For one of the treatments he attempted it was Ribavarin and he also received Interferon. I don't know if he received both at once or which one was attempted first. He attempted two courses of this treatment and both times it failed.
23. I have no idea if he faced obstacles or difficulties in accessing treatments.
24. I don't know about any treatments that were available but not offered to Dad, but when Dad underwent the treatments both times, he should have had counselling, to cope with going through that. But then I don't know if the doctors knew about the side effects.
25. The biggest effect for Dad of the treatment was the mental impact. He became a recluse, spent all his time in bed this is my main memory. Then when he attempted the 2<sup>nd</sup> course of treatment, he was just a completely different person. It was horrific, he was having hallucinations and not able to function at all. It completely changed who he was and was devastating to watch him go through this to then find out that this had failed as well. He went through the 1<sup>st</sup> lot of treatment in the 1990s and I can recall that he had just turned 40 when he found out that the 2<sup>nd</sup> course of treatment had failed. Physically, Dad lost a lot of weight, he was stick thin. He was always tired, he had terrible fatigue and spent most of his time in bed. At the time he was working in a factory and he was too ill to go to work and had to be signed off as being long term sick. At one point he tried to go back to work too quickly

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and had to be signed off again it was too much for him. He was sick a few times and always had to go back and forth to bed continually.

26. I am not aware of any impact for any other medical conditions for Dad.
27. No one knew he was infected. Only Mum knew and my older sister [GRO-B] and I, but even that was limited. All we knew is what Mum told us which was that there was something wrong with Dad's blood and that was it. I don't even think that my Granny and Grandad knew the full extent either. They just didn't tell anyone; I think because of the stigma. Dad was already a really private person, but then the stigma of where hepatitis came from, just meant it was a total secret. The infection itself got hidden from us a lot, so the impact was minimised. I didn't realise the full impact until after Mum and Dad broke up and then Mum told us the extent of what was going on.
28. It is hard to say what the impact has been on other family members. No one knew so there wasn't an impact really until he passed away. Then people started to talk about it and hepatitis was highlighted in the media, our awareness grew and we spoke about what had happened to him. Mum doesn't really talk about what the impact has been on her, we are quite open and talk about it, but even though [GRO-B] and I are in our 30's she still tries to protect us from it where she can. [GRO-B] and I speak about it as well, but she will say how it affects her separately if she wishes.
29. Before Dad started treatment he would work 7 days a week he was such a hard worker. When he got signed off that added to the depression because he couldn't provide. I can't remember when he did go back to work, but I do remember he went back and had to be signed off again because it was too soon. Eventually he was made redundant, I can't remember when this happened. A lot of people in his factory were made redundant at this time, he never went back to work again after this. After this he applied for benefits for his remaining days.

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30. There were no or educational effects on myself that apply for this.

### Section 6. Treatment/Care/Support

31. I'm not sure how long it was between when he was told about his diagnosis and his first treatment, so I don't know what care, treatment and support was offered. I must have been really young. I only remember the 2<sup>nd</sup> treatment really and that was something that there was no outside support. Psychological support should have definitely made available to Dad and would have helped Mum as well. Psychological support would not have benefited me though.

### Section 7. Financial Assistance

32. I don't know how he found out about the existence of the funds, I would imagine it was his haemophilia nurse, Liz who probably told him.
33. Dad received £10,000 from the Skipton fund, when I was younger, I am not aware of him receiving any other financial assistance.
34. I don't know what Dad had to do to apply for financial assistance.
35. I am not aware of any difficulties or obstacles he might have faced for financial assistance.
36. I don't know if there were any preconditions to applied to making a grant for financial assistance.
37. It took far too long, the financial help that is in place now helps, but it is far too long given how sick people have been. Mum has only started to receive financial support from SIBSS from December 2018 which was just far too long because he was stage 1.

**Section 8. Other Issues**

38. Mum holds all documents in relation to Dad and this will come from her if there is anything she wishes to provide.

**Statement of Truth**

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

Signed GRO-B

Dated *20/4/19*