Witness Name: Elizabeth Newby
Statement No.: WITN5503001
Exhibits: WITN5503002
Dated: 23rd March 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ELIZABETH NEWBY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18th January 2021.

I, Elizabeth Newby, will say as follows: -

Section 1. Introduction

1. My name is Elizabeth Newby. My date of birth is the GRO-C 1947 and my address is known to the Inquiry. I am living at home with my husband George who is also providing a statement to the Inquiry. I intend to speak about my son Steven Newby whose date of birth is the GRO-C GRO-C 1973 and how he came to be infected with hepatitis C. In particular, I will speak about the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our family.

Section 2. How Affected

2. Steven has haemophilia A and was diagnosed with the condition when he was 6 months old. His condition is considered to be severe. There is a history of the condition in my family, GRO-C GRO-C

3. Steven was diagnosed as a baby. George was bathing him and when he dried him on a towel, his fingerprints remained on Steven's body. We immediately took him to GRO-D where they decided that we must have been abusing him. It was however discovered after investigations and blood tests that he had haemophilia.

4. Steven was treated at GRO-D and was under the care of Professor GRO-D after 1980. Prior to that he was under the care of Dr GRO-D

5. As a family we are GRO-C, and as such we did not want Steven to receive blood products. As a result, Dr GRO-D prescribed him with cryoprecipitate, tranexamic acid and Factor VII. Dr GRO-D treated our beliefs with respect.

6. The Factor VII was fine, but he was still having bleeds. When Dr GRO-D took over, the hospital started to say that we were not parenting correctly for that reason. Before 1980, if Steven had a significant bleed we would take him to hospital and say to them, please just give him painkillers and bedrest. They agreed to this and put him in a cast/support as required. When Dr GRO-D took over he disagreed with this way of treating Steven.

7. Dr GRO-D decided that this had to change. It started with Steven's teeth. Steven was to have 7 teeth removed. We disagreed with this as Dr GRO-D had advised us once before that we couldn't have Steven's teeth taken out because for some reason on the tenth day after this occurs, those with haemophilia haemorrhage and this would put his life in danger. Dr GRO-D recommended that it would be safer that only one

tooth be removed. Dr GRO-D disagreed and gave us repeated reassurances that there would be lots of safe guards put in place to protect him. The procedure went ahead and sure enough on the tenth day Steven had a haemorrhage exactly in the way we were warned about. Dr GRO-D did not listen to us, he choose to ignore our voices. We found that he was always pleasant to our faces, but would then make decisions and proceed with things that we were not happy with.

8. We never had any sort of discussion with Dr GRO-D about treatment options. What he did do however in the early 1980s when the HIV scare was going on was that he brought all of us in to be tested for HIV. We were never told the results.

9. Dr GRO-D obtained a court order to force Steven to receive Factor VIII and he made our lives hell. From when Steven was nine years old, we attended five Children's Panels over this. There was a social worker called Mrs Brown who would visit us on a Tuesday and a Friday for two years, to supervise us in administering treatment to Steven properly. We had to write down all the details of his treatment, how he was feeling that day, times he had gone to school etc. It was like a diary. This diary was for social work's purposes to watch us.

10. After Steven was married around 1993 when he had turned 21, he went to hospital for a routine appointment with his new wife. During this consultation the consultant made a throw away comment about 'his hepatitis C'. Steven had no idea what it was. It was a horrible shock for him and his wife. The next advice they were both unceremoniously given, was that they should not have children for at least one year. I believe that this advice was given due to the doctor's understanding of hepatitis C being limited at this point.

11. When I found out Steven had been infected with hepatitis C, I was unbelievably angry. The problem is decisions about his treatment had been taken out of our hands by that point. I felt for my son when I found

out, because seemingly from the age of 12 (1985) we were advised that there was something wrong him, during a consultation but we weren't told what it was. We were kept in the dark all the time.

12. George and I feel that giving us information about Steven's infection of hepatitis C was deliberate. They delayed things and made our lives so miserable we were successfully cut out of receiving the real information. The hospital would always say that Steven was just going along with what we wanted, to please us, which was rubbish. He had the right to make his own decision. He knew what he wanted, and George and I always respected what decision Steven made about his own life.

Section 3. Other Infections

13. I am not aware of Steven being exposed to any other infections. Steven does not share everything that he is going through physically.

Section 4. Consent

14. Please refer to George Newby's answers in section 4 for my comments on this as they are the same as his.

Section 5. Impact

15. It was extremely difficult raising Steven with his physical difficulties. It wasn't just him as well, I had two young daughters to care for as well that would feel impact when we had to attend hospital. For example if we had made an arrangement to go out and do something as a family and Steven had a bleed, it would impact everyone. We found that we would make arrangements for the girls so they could go out with their friends and enjoy their lives, however Steven and I were joined at the hip. We were always together. He went to a special school and got on great there, really a great school. They would treat him with ice packs and if there were any issues they would phone me. If there was a school

outing I had to go with him, if there was a school meeting I had to go with him, I was always with him. When this issue started with Dr GRO-D I felt that things were taken out of my hands because now this man, was being a parent to him, when he wasn't. Steven was frightened of him.

16. There was a time when Steven was fifteen years old, and he went to stay with his sister. They were decorating her house and the fumes from the paint hurt his throat causing him to haemorrhage. He went into hospital because he couldn't breathe and he said to them that all he wanted was Factor VII. The hospital refused saying that this was too serious and that he would need Factor VIII. Steven wrote a note to his sister in the ward saying "I think I am going to die". When we arrived at the hospital, both Steven and our daughter were quite distressed. The doctors had gone to Steven two or three times in the night and had asked him to sign a document so he could receive blood products or he was going to die. What he did that night instead of signing, was write a letter which I exhibit as **WITN5503002** talking about how he was prepared to die and would rather die than take treatment. Neither George nor I knew about this, it had been entirely played down until we got there. He got through this episode without treatment in the end. It turned out he had developed a haematoma in his throat because he had an irritable throat and it was causing him to continually cough. It pressed on his windpipe and it was restricting his breathing. He was being threatened all night. The letter I exhibit shows what he wanted when he was fifteen.

17. We went to court 3 times over this and we would stand up there and explain our position and the worries. The NHS argument was that the products were heat treated, but no one would listen to us saying "We do not want our son to have anything to do with this treatment whatsoever".

18. The fight to try and protect him, it made us ill. It really made us ill. I have a heart problem now, I've developed lupus, the stress of everything caused my immune system to attack itself. The attitude from the hospital

was always ‘We don’t care about what you and your son want’, it was a horrible feeling.

19. There were 4 charges made against George and I during the 1980s. I can’t remember now what they were exactly but the judge said to us that because Dr GRO-D knew about the treatment it was his word over ours. The decision was taken out of our hands altogether.

20. We tried to treat Steven the same as everyone else. He went to a special school and at one point the authorities got together and discussed, that he was doing so well, maybe he could go to a mainstream school. We agreed that this was fine, and he attended the school down the road from us. No one at this school was to be told that he had haemophilia however he wasn’t allowed out at playtime and he wasn’t allowed to do certain things, which immediately separated him from the other children who must have instantly asked themselves why that was.

21. I was the only mother who went on outings while he was at the mainstream school, I had to do everything for him and was much more involved than other mothers had to be.

22. He had treatment kept at the school for him and I recall that one day a teacher panicked because he had a paper cut so she sent for me and called an ambulance. The school dealt with it so badly that the headmaster got everyone in the assembly hall and said to the entire school that Steven had an illness and no one was to touch him or hurt him. It was the worst thing she could have ever have done because he was then attacked. Walking to school one day he was beaten up and thrown over a hedge. He was in a horrible state after this black and blue with his head was swollen, so I instantly said no this does not work, he needs to go back to the special school and that is what happened. From moving to the mainstream school and back to the special school these events took place over a 2 year period.

Section 6. Treatment/Care/Support

23. When Steven was younger, there was a psychiatrist called Dr Scarf, from the GRO-D who would come and see us weekly and help us develop coping mechanisms. He was very kind, however the underlying theme was the hospital were saying to Steven, ‘this is going to happen so send the family a psychiatrist and have the psychiatrist drum it into Steven that he has to get used to needles and receive treatment/

24. Steven told me recently that he saw a news report about the Inquiry and he had to walk away. It brings so many bad memories back for him. One of them is him being held down when he was younger to receive treatment. He was being held down so the doctors could find a vein and use a needle on him. When the news speaks about what has happened to children with infected blood, he keeps getting this flashback of being held down and of me shouting, desperately trying to get to him. He has been traumatised by what they did to him.

Section 7. Financial Assistance

25. We have had no involvement with any financial matters and we have received nothing from the Trusts and Funds.

Section 8. Other Issues

26. I have no other matters to raise for the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 5 · 04 · 21