

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0088001

Exhibits: WITN0088002

Dated: March 2021

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1: Introduction

1. My name is GRO-B. My date of birth is GRO-B 1949 and my address is GRO-B. I am married to GRO-B who has also given a statement to this Inquiry (GRO-B).
2. I am making this statement to talk about the impact that contaminated blood has had upon my three sons. The eldest is GRO-B:S1 born on GRO-B 1976. He was followed by twins, GRO-B:S2 and GRO-B:S3 born on GRO-B 1980.
3. My statement has been prepared for this Inquiry from my own recollection, and following a review of a witness statement that was prepared on my behalf during litigation undertaken in the early 1990s (WITN0088002).

Section 2: How Affected

4. All three of my sons suffer from severe haemophilia A. They all have less than one per cent clotting factor. My mother-in-law's brother also had Haemophilia.
5. Before [S1] was born we were aware that there was a history of haemophilia in the family on my wife, [GRO-B] side. Her uncle had had haemophilia and died when he was three years old. At that time, the treatment was simply bedrest. We asked for [S1] to be tested at birth and a blood sample was sent to London. He was referred to Great Ormond Street Hospital ("GOSH") and diagnosed with haemophilia.
6. The instant response from people when you say haemophilia is *"oh, is that when they bleed to death?"*. Not very much was known about it when the children were young. GOSH were helpful in informing us about the condition. My wife's mother could not really tell us anything about it.
7. [S1] first had treatment for a bleed when he was a few months old. I believe it was Cryoprecipitate that he was treated with. We were not told of any risks of using that product and because the product was frozen, it could not be used for treatment at home.
8. [S2] and [S3] were also diagnosed with haemophilia as babies and initially treated with Cryoprecipitate at GOSH. [S3] also received some treatment at Wexham Park Hospital in 1983.
9. I think that between the boys, we attended hospital to treat bleeds maybe once or twice a week. [S1] in particular was a very stubborn child. He would never admit to having a bleed, and suffered joint bleeds all the time.

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10. We became aware of Factor VIII in October or November 1984. The doctors spoke to GRO-B about this as I was at work at the time. When she told me about it, she explained that the treatment could be administered at home and so it would mean we were not running to the hospital all the time. This was magic. It changed our lives at home.
11. S1 was initially treated with Factor VIII at hospital, and then at home from the age of about five or six. GRO-B was taught at GOSH how to treat S1 at home, and I would often help with his treatment at hospital. Neither of us were told about any risks of using the product. S2 went on to Factor VIII in early 1984, and S3 was treated with Factor VIII from November 1984.
12. In early 1985 all three of the boys had been tested for HIV at GOSH and we were told the test results were negative. Later that year, sometime between September and November 1985, we had a call from GOSH to say that one of the routine blood tests had come back abnormal and that we should go into the hospital to discuss this. At the time, I was working in Liverpool but I flew back to London and we went to GOSH the very next day.
13. When we received this call I thought it was S2 that had had abnormal test results returned. GRO-B thought it was S3. S2's growth had been a worry for me and GRO-B had been worried about S3's swollen glands.
14. At the time, there was a lot in the media about HIV. The adverts with the old man and the scythe were all over the place, and so my mind automatically went to HIV when I was told that blood test results were "abnormal".
15. A few days before S3's fifth birthday the hospital confirmed that S3 had tested positive for HIV, however S2 and S1's test results were negative.

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16. The treating doctor at GOSH, Dr Evans told us what we already knew from the media; there was no treatment for the infection and the prognosis was not a good one. The negative press around HIV was more or less what the doctors repeated to us. There was a lot in the news about celebrities who had died of AIDS and we came away numb, not knowing what to do, and thinking we were going to lose our son.
17. We were not advised about any risk of transmission in relation to S3 but GRO-B was very careful about dealing with all treatment wearing gloves, and I did not treat the children at all. The boys later started treating themselves prophylactically three times a week before going to school in the morning.
18. We did not initially tell S3 about his diagnosis. We decided to tell him when he was about 12 years old. He was devastated when he was told at first but he has an attitude of "let's just get on with it". S3 is an optimistic person.
19. I cannot remember exactly when we were told that the boys had contracted the Hepatitis C infection. GRO-B thinks that it may have been around the time that S1 moved from GOSH to St Thomas's in 1987 that we found out that he was infected. I know that S3 was quite shocked when we told him about his condition. He was upset and wanted to know if he was going to be okay.
20. As the children grew older, we became less involved in their medical care. We have always been a close family, but the boys dealt with their own medical appointments as they grew up, and I never wanted to press them on these matters.

Section 3: Other Infections

21. I am not aware that the boys were ever tested for or contracted any other infection aside from HIV and Hepatitis C.

Section 4: Consent

22. Whilst we gave consent for treatment of the boys, I do not think we knew what we were consenting to because we had no real information about the risks of using blood products.

Section 5: Impact

Impact of S3 HIV diagnosis

23. S3 HIV diagnosis was devastating to me. It was the next worst thing to having a death in the family. We found the news out about S3 two weeks before his fifth birthday and I found myself asking if he would be here for his sixth birthday. You heard of celebrities like Rock Hudson dying around us. There was a negative atmosphere surrounding the condition and a lot of stigma underlined in large headlines every day, blaming homosexuals for "a gay plague". We kept our heads down and got on with life but life itself had irrevocably changed.
24. The impact of S3 HIV on our marriage was difficult. GRO-B wanted to talk about it, but I did not. We lived more or less separate lives. I effectively cut S3 out of my life, thinking that when he was gone then I would not have to feel the pain of his loss; that I would not notice. I tried to block it all out. I spent years pushing him out of my life. In truth, I just could not cope and for years my first thought in the morning was about HIV, and my last thought at night was the same. I was sent to hospital with clinical depression, as described below.

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25. I lost concentration at work but was always concerned that I had to keep working to ensure we were financially stable. I had felt a lot of pressure since the boys had been diagnosed with haemophilia. GRO-B could not work and so I was working for both of us, six days a week, and having no breaks apart from a Sunday to recover. I was travelling everywhere and this did not help the strain I was under. The strain was financial, mental and physical, and it was significant. Because I was self-employed, there was a lot of pressure on me but I did not feel that I had a choice. I had to support my family. I appreciate that this left GRO-B to do everything for the boys. I knew that the boys' condition was being monitored, but I did not know very much about their infections. I did not know what the consequences would be.
26. Eventually I learnt to live with it. I recovered by watching S3. He was a happy child and was getting on with his life. Things got better and as time went on and S3 health wasn't deteriorating as quickly as I thought it would, I became a bit more optimistic. My relationship with S3 and my wife improved as a result.
27. As set out below, my wife and I took part in the HIV litigation in the early 1990s on behalf of S3 (the "Litigation"). After giving my statement to the litigation solicitors, I kept busy although it had dredged up a lot of sad and negative feelings. I am a positive person but I went into self-denial I think.

Stigma

28. There was a lot of social stigma attached to HIV at the time. I recall that one parent went into the children's school and demanded to know what the boys' HIV status was. She would have known that they were haemophiliacs and had made a leap, presuming that they must have the infection that she had heard about on the news. The headmaster told her it was none of her business and that he would tell parents if he had any concerns.
29. We were lucky that friends and people that knew us assumed our children were not infected. I told my mother about my sons' diagnoses and also my best friends

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about it. One work colleague also knew about S3 condition as he was with me when I found out on the telephone that one of the boy's test results were abnormal in 1985. GRO-B brother does not know. In my view it is not our right to tell anyone. It is the boys' decision, and their business.

Impact on my sons' education

30. I do not believe that the infections that the boys had had any impact on their education, at least no more than haemophilia already had. As they got older, they did have periods where they were quite unwell. S3 in particular was very unwell after finishing university and whilst he was at bar school. He would go to bed very early in the evening as the day would exhaust him.
31. I recall that one night I had to carry him up to bed after he had been on a driving experience. There was a very strong seat belt restraining him which I think must have done some damage. He could not lift his head and he passed out because his blood pressure was so low. Dr GRO-B came round to the house and called an ambulance. He was taken to hospital on a stretcher and kept in ICU overnight. I think he had just started university and was about 17 years old at the time.
32. A year or so later I recall another incident when S3 was GRO-B on holiday with a friend when he was about 18 or 19 years old. He contracted GRO-B and was taken to hospital. His friend called GRO-B to tell her that he had been given Factor VIII and was being kept in hospital. We brought him home soon afterwards as one of our neighbours worked for GRO-B and was able to get him a comfortable seat on a flight home.

Treatment for Hepatitis C

33. As far as I am aware, **S1** has now cleared the Hepatitis C infection after two rounds of treatment at St Thomas' Hospital in London ("St Thomas"). There was a gap between the treatments because **S1** was not dealing with the treatment well. His liver function is at stage 2 deterioration. There is a risk of cancer later in his life and severe liver cirrhosis. I do not think there was any lasting effect of the treatment; he is very private and does not say a lot.
34. **S2** received treatment for Hepatitis C at UCH. He tolerated it well the first time but it was not a pleasant experience. He did not clear it until recently. We have been talking to **S2** about gene therapy for the treatment of his haemophilia following a recent AGM at The Haemophilia Society. It is still early days for gene therapy in my view. I do not want him to be a guinea pig so I would not recommend it to him actively. I think they should test it on others and figure out what the problems are before they use my son. He has already suffered enough.
35. The later Hepatitis C treatment for **S2** seemed to have worked. He does product launches for **GRO-B**. He is based in London but often travels internationally for work, although not as much as he used to. He seems to cope well with his job. He was originally employed by **GRO-B** but now works for them through an agency. They have treated him well. He does a lot of football refereeing, runs half marathons and is quite fit. **S3** has also cleared Hepatitis C and he does Iron Man competitions. They are both very fit considering the health problems they have had.
36. The age gap between the boys has shown a massive difference in levels of fitness between **S1** and **S2** and **S1**. It is sad that **S1** struggles more because he was born earlier. The bleeds into his joints have had a massive impact on his ankles in particular, although he does not really talk about this.

Impact on S1

37. S1 was about eight or nine years old when he asked us if he had AIDS. I told him he did not.
38. I would say that the infections have affected S1 more than any of the other boys. S2 and S3 got on well with it but S1 does not talk to anyone and did not want to talk about his condition. When he was old enough to choose who to tell, he chose not to tell anyone, apart from his wife.
39. I feel for S1. He has four children and a lot of responsibility on him. I worry that he gets upset and angry because he does not know if he will be alive to see his children grow up. He has a lot to live for and worries that he will not be there for his family. Seeing him like this bothers me a lot. Of all my sons, S1 is the one I worry about most.
40. All three boys are in long-term relationships and happy in their family lives as far as I am aware. I feel as though we are through the worst of the health problems the boys have had so far. That is not to say I do not worry about what the future may hold, but for now, our lives are stable and the boys are doing well.

Section 6: Treatment / Care / Support

41. My wife knew more about the boys' condition than their local doctors did. We did not really have a lot of contact with the GPs, the boys' care was mainly at GOSH. The doctors always asked how the boys were and how I was doing, they came to know our family quite well.
42. I was not offered counselling when the children were diagnosed with their various conditions. I have spoken above about the psychological impact this had had on me at various stages. Nevertheless, had I been offered counselling during the darkest period for me, I cannot say I would have taken advantage of it.

43. As set out in my statement for the Litigation, in 1986 I went to see my GP about how I was feeling and he referred me to a psychiatrist at Wexham Park Hospital, who simply told me I was having a reactive depressive episode. As I was not getting better, my wife got me to see Dr Lynne Ball at GOSH. She was more helpful and sent me back to my GP to prescribe antidepressant pills. However, this did not help. I could not concentrate and they made me sleepy; it was not good for the job that I did. As set out above, things improved for me over time.
44. I do not put a lot of faith in psychiatric help. It is good for some but it does not work for me.

Section 7: Financial Assistance

45. GOSH made us aware of the Macfarlane Trust in relation to S3 because of his HIV diagnosis. We applied for holiday payments, and discretionary payments through ad hoc applications. In particular, GRO-B and I wanted S3 to have a big holiday because we did not know how long he would live, and we applied to the Trust for payment to do this. We also applied for payment for a car deposit and a refrigerator to keep the boys' treatment in. I do not recall the applications being onerous or difficult.
46. In respect of the HIV litigation in the early 1990s, I cannot remember how we became aware of it. We were represented by a firm of solicitors called Pannone Napier. S3 did not know about his diagnosis at the time. We did get as far as issuing proceedings at court, and an offer was made to settle in the amount of £20,000 which stopped proceedings.

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47. We went to a meeting in London that had about 50 people there. The government had agreed a payment of £20,000 as long as the claim did not go any further. My immediate reaction was that this was not enough and we did not want the door for further litigation closed. However, the solicitors told us it was a "take it or leave it" scenario. We were also given the impression that we would not be allowed to proceed with the case on our own, or outside the litigation framework in place with Pannone Napier. We felt we had no choice but to agree settlement.
48. Payments were made on a graduated basis. Not everybody was given £20,000, and I think the split was unfair. It was dependent on people's circumstances. We came out with a total of £22,000. My greatest concern was that I do not think the damages paid reflected what S3 had suffered. In particular, it worries me that we cannot go back to litigate against anyone if S3 condition gets worse.

Section 8: Other Information

49. It is hard to know what life would have been like without the boys having been infected with blood products. It has been harder lately with all of the news about the Inquiry. Watching the Inquiry proceedings is very difficult for me. I look forward to seeing what the Inquiry can achieve to give our family some answers as to why this was allowed to happen.
50. I do believe that GOSH lives up to its reputation. The hospital was good to us and treated us all very well. We were never turned away and they gave us the best treatment they could at the time. I do not think they are the ones to blame as they were simply using blood products that they had been told to use or provided with.
51. I know that GRO-B wonders what the Inquiry can achieve. She does not think that justice can be done because she thinks, "*how can you blame anyone? Who do you blame?*" I disagree with her. In my view, there are plenty of culprits that include John Major and Kenneth Clarke. These are people who lied and

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disseminated false information. There are people who profited from the contaminated blood scandal. In Sweden, people were sent to jail; why has that not happened here for the same crime? I feel strongly that people should pay for something like this which has happened on an unprecedented scale.

Statement of Truth

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

Signed :

GRO-B

Dated:

8-3-2021