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Witness Name: GRO-B

Statement No.: WITN2311001

Dated: 25th March 2019

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 2nd November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B
GRO-B 1970 and my address is known to the Inquiry. I am
married to GRO-B: H I intend to speak about my
husband's experience of becoming infected with hepatitis C and HIV.
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.

Section 2. How Affected

2. My husband was born on GRO-B 1967. He suffers from severe haemophilia A.
3. He received cryoprecipitate from birth in order to treat his haemophilia and then he moved onto Factor VIII when he was at an age younger than 14. I do not know the exact age when he moved onto Factor VIII.
4. He was always treated at the Aberdeen Royal infirmary. Growing up, his visits to the Aberdeen Royal infirmary were quite frequent. The reason for this is that at first he had the treatment there, and then he received injections that he could self-administer at home. He attended the Aberdeen Royal infirmary for joint issues or any other issues related to his haemophilia. I do not know how frequent his visits to the Aberdeen Royal infirmary were during his childhood. When I met him, he required treatment for several days in a week or once every two or three months as needed.
5. I do not know the names of any doctors who treated him growing up.
6. My husband came to be infected through his Factor VIII injections. The blood product was infected. I do not know the date on which he became infected.
7. Neither my husband nor his parents received any advice or any warning about the risk of the blood products being infected.
8. My husband was infected with both hepatitis C and HIV and he found out that he was infected with HIV just before we got married; this would mean he found out about his HIV in 1985 or 1986.

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9. I found out that my husband was infected because he told me. To begin with, we only knew about the HIV and later on we found out that he was also infected with hepatitis C. I believe that it was his consultant at the Aberdeen Royal infirmary who told him. He must have given my husband the news at a routine appointment that my husband attended on his own. My husband told me the news later on. I do not remember how long after my husband's HIV diagnosis we found out that he was also actually infected with hepatitis C.
10. I do not believe that there was much information given about the infection at the time and he certainly did not get any leaflets or anything to read. He was just told that he was infected with the virus. My husband's consultant at the Aberdeen Royal infirmary was Dr Audrey Dawson. Then when she retired he came under the care of Dr Henry Watson.
11. I do not believe that my husband was given any information to help him understand and manage the infection on a day-to-day basis. He was just told that he had the infection and was offered no guidance, so we were just left to find out about the infection on our own.
12. I believe that information should have been provided earlier, definitely as soon as the government knew that there was a risk of infection, when they took the chance and decided to use infected blood products.
13. My views about this whole situation are that it was very poorly managed and that there should have been a better support network in place and things should have been disclosed as soon as the government knew.
14. I do not believe that my husband was given any information about the risks of others becoming infected as a result of his infection. I do not

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think that anything was said and he did not receive any written information. I am not sure what would have been said..

Section 3. Other Infections

15. My husband was infected with HIV and hepatitis C as a result of being given infected blood products.

Section 4. Consent

16. I believe that my husband was treated and tested without his knowledge, without his consent and without being given adequate and full information. The reason why I believe this is because my husband was simply told out of the blue that he was infected without being called in for any tests prior to his diagnosis and he was told at a routine appointment.
17. I do not know whether my husband was treated or tested for the purposes of research. He was definitely tested without his consent and I think that once your blood is taken, you do not really know what happens to it.

Section 5. Impact

18. Becoming infected with hepatitis C and HIV had a huge mental and physical impact on my husband, to the point where he almost died. The mental impact was huge because it is always and your mind that you are infected. As a result of both the treatment and the infection, my husband almost died. The hepatitis C progressed so far that my husband required a liver transplant. The interferon made him really ill and he was given hours to live at one point. Interferon also caused him to developed septicaemia and this meant that his heart valves

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had to be replaced. This caused him to develop diabetes. My husband did not have depression, and I think that up until his treatment for hepatitis C he was very much mentally stable.

19. My husband developed septicaemia from the interferon. The interferon had an effect on his mental health as the treatment made him so ill that he was unable to concentrate on anything. He also suffered from extreme tiredness and fatigue and couldn't walk any distance. Further, he suffered from severe cramps and couldn't sleep at night. He also suffered from nosebleeds and eventually he couldn't even sit up on the sofa so we had to set up a bed in the living room while he was on interferon. My husband was not able to get out of bed and he was not able to even use the toilet on his own when he was on this treatment.
20. Due to the hepatitis C, my husband developed cirrhosis of the liver, septicaemia and encephalopathy. The reason why he developed encephalopathy is because the liver cannot purify toxins in the body and they go up to your brain. This made my husband confused and he did not recognise people, to the point where he did not recognise me or our daughter. He also experienced very severe variceal bleeds and required several transfusions. For these purposes, he was taken to Aberdeen Royal infirmary and I remember that right before his liver transplant, the doctor said that my husband wouldn't stand many more of these episodes.
21. The hepatitis C has cleared now. As a result of the interferon treatment that my husband had in 2005, we thought at the time that he was clear of hepatitis C, but he really wasn't. After his liver transplant, the hepatitis C came back. Later, he started a new treatment which has now cleared the hepatitis C, this was simply tablets and he went on that treatment about three years ago.

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22. My husband went on his first treatment between April and March and until November 2005. He could only receive ten months of treatment as he became so ill that he could not finish this. It was this first treatment that caused his septicaemia.
23. My husband second treatment lasted for about nine months. The second treatment made him very tired and weak, but not to the extent that the first treatment did. He just suffered from tiredness and weakness and his hair went thinner.
24. For his HIV, my husband takes liquid Keletra twice a day and his viral load remains undetectable. He has been on this medication for many years. I think he has been on Keletra at least since before his transplant. He has only ever received two treatments for his HIV these are AZT and Keletra.
25. I do not believe that my husband has faced any difficulties or obstacles in having access to treatment.
26. I do not think that there were any treatments which should have been available to my husband but were not.
27. In order to receive his dental treatment, my husband goes to hospital. He only goes when needed and he does not normally have any routine appointments. I am aware that this is not standard practice and I would say that to that extent becoming infected has affected his medical treatment. My husband's GP has always been good and it is only really the stigma that we worry about.
28. I believe that there is a stigma associated with a diagnosis of HIV and hepatitis C. The reason why I believe this is that these infections are not something that you would openly speak about. The infections also had a huge effect on what my husband could do and made it more difficult to get a mortgage or get holiday insurance and they did hold

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my husband back at work as he always needed to be close to a major hospital.

29. My husband's infection also had an effect on our private and family life. We are blessed to have a close family and very supportive friends, which means that we are well supported. My daughter and I are not infected, but my husband's infection made us take the decision not to have any more children as we feel that we couldn't take the chance for them not to be healthy. The infection has not affected the time that we spend with family and friends and I feel that it has brought everyone closer, despite being a horrible situation.
30. I required to take one year off work when my husband was ill in order to look after him. My husband received his transplant at the Edinburgh Royal Infirmary, where he was treated by Dr Hidalgo and Dr Bathgate. The medical team was very supportive and my husband's consultant from the Aberdeen Royal Infirmary, Dr Andy Fraser, was also involved. At the time of my husband's transplant, I moved to Edinburgh so that I could be closer to him. Our daughter had to stay home and she thought that her dad lived in hospital.
31. My husband himself was off work between November 2005 and August 2007, as he could not work due to his illness and hospitalisation.
32. The infection had no effect on my daughter's education as my mum and dad moved in to our house to look after my daughter when I was in Edinburgh at the time of my husband's transplant. I do believe that my husband could have done courses to further his career, but he was too ill to even think about it.
33. My husband's infection had a huge financial effect on our family. I could not work for a year, and while my husband's work paid his salary in full while he was off, he lost on his bonuses. As I had to stay

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in Edinburgh with my husband, we had no opportunity to build up an income as any other family our age would have done as our income was very low at this time and we had many expenses. I had to rent a property in Edinburgh and stay there for a year at the time of my husband's transplant and for as long as he was in hospital following the transplant. I estimate that we lost about £50,000 or £55,000 in expenses and loss of earnings.

Section 6. Treatment/Care/Support

34. Counselling and psychological support were never offered to us as a result of my husband becoming infected with hepatitis C and HIV.
35. Counselling was offered at the transplant unit, at the time of my husband's transplant. However this counselling was purely transplant-related and we did not take it as we had a good support network of family and friends and we felt that we did not need counselling that would be purely about the transplant..

Section 7. Financial Assistance

36. My husband received disability living allowance because he's a haemophiliac. However, this stopped soon after the transplant.
37. At one time I applied for a carer's allowance, but I was told that I had to make our bad day the worst it could possibly be and I was not prepared to do this as things were so bad I didn't need to make them worse. Therefore my application was a fiasco. We were also told that if I left work of my own free will any application would be declined.
38. My husband has received financial assistance from the Skipton Fund and the Scottish government. I believe that he received a lump sum of £20,000 at one point and then we are now receiving regular monthly payments of about £3,083 a month. I do not know much about this

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because I don't personally deal with financial affairs; it is my husband who does.

39. About the process of applying for financial assistance I just remember that there were huge forms to fill in with all the details. However, it was my husband who dealt with it all.
40. I do not think that we faced any obstacles in obtaining financial assistance. I would only say that it was a very long process.
41. I do remember that at some point we applied for either a boiler or a heater and our application failed as we were considered not to meet the criteria.
42. I do not know whether any preconditions were imposed on the making of an application for or the grant of financial assistance.
43. I believe that financial assistance has been a major help, but I also feel that my husband has been held back due to his infection. I think that infected people have gone through a lot and the process for obtaining financial assistance takes a very long time. I think help should have been handed out to the infected people without having regard to any criteria because people became infected through no fault of their own and it was not a consequence of any life choices they made.
44. I have not received any financial assistance, it was just my husband who did. In fact if something were to happen to my husband the monthly payments would cease, meaning I would have very little income.

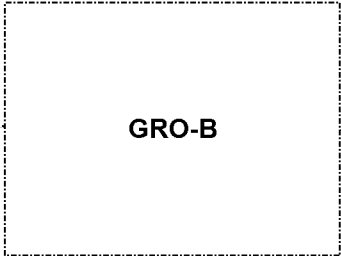
Section 8. Other Issues

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45. I was registered with the Penrose Inquiry but I never gave a statement for it. My husband gave a statement for the Penrose inquiry.
46. I have never been involved in any court proceedings or campaigning as a result of my husband becoming infected.
47. I would say that my husband's infection had a huge impact on our family, especially at the time of the transplant and I think that this whole situation could have been avoided if proper precautions had been taken. I also believe that an apology should be given as no one has admitted responsibility for what people have been put through. Maybe they were hoping that there would be no one left so an apology would not be an issue.
48. I have seen my husband's medical records and there are parts missing from the time when he received Factor VIII to treat his haemophilia.
49. I would like to remain anonymous for the purposes of this Inquiry. From my point of view, I do not have an issue with anyone knowing that [H] was infected with hepatitis C, but I would be very upset if anyone knew that [H] is HIV positive.

Statement of Truth

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

Signed  _____

Dated 10/7/19.