Witness Name: GRO-B
Statement No: WITN1274001
Exhibits: 0
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B and I was born on GRO-B 1965. I live at GRO-B I got married to GRO-B: H on GRO-B 1983 and I have a son and a daughter and one granddaughter. I am now self employed and work from home in alternative therapies and healing. We also run a GRO-B

2. I am aware that my husband, H and son GRO-B also intend to provide witness statements to the Inquiry. I am also aware that my husband's sister-in-law, GRO-B and her two sons, GRO-B and GRO-B GRO-B also intend to provide statements in regard to my late brother-in-law GRO-B

3. This witness statement has been prepared without the benefit of access to my husband's full medical records.

Section 2. How Affected

4. My husband has severe Haemophilia A and was treated in the Heath Hospital in Wales (now University Hospital of Wales).

5. He believes that he was given the HIV infection in 1979 from his notes from the American litigation. He was given no information or advice about the infection, and only recently he found out that he was also infected with Hepatitis B.

6. He was informed that he had been infected with HIV by Professor Bloom at an appointment in or around 1984. My husband and I were married at the time of this appointment with Professor Bloom and I went to the appointment with him. I remember being told that they did not know much about it but that H should use separate cutlery, toothbrush and towels.

7. The meeting we had with Professor Bloom was very cold and matter of fact; he was straight to the point and did not even try and flower things up a little. The meeting was very short. Perhaps informing people with news of this nature is normal for doctors as they are dealing with these sorts of things on a daily basis, however, for us hearing things like this was huge. We were briefly told of precautions we should make and possible risks from the infection.

8. We were definitely not given enough information about the HIV infection but were just told not to worry; and that seemed like it was just to try and reassure us. We were told not to speak to anyone else about the infection as they were trying to figure out more about it. They just made us feel unclean in some way.

9. I believe that they knew that something was wrong but they did not tell us for ages. We should have been told earlier. My son was born in GRO-B 1983 and so it was very close.

10. After the meeting when H was told he had HIV, I then had HIV tests at first every 6 months and then annually. I was told that this was because HIV

takes months to reveal itself in the body and the tests at the time were not very good.

11. It was only when the Birchgrove Group was set up that we realised so many other people were infected too. The Birchgrove Group started off really small in the back room of the Birchgrove Pub, Cardiff with about 10 to 12 people.

12. H found out about his Hepatitis C infection much later. He received a letter saying he should go and see Professor Bloom. We went to see him and Dr Dasani was there too. He said that there was nothing to worry about and that it might not even come to anything and it was not an instant thing. He played it down. We couldn't see anything above HIV. I now know that Hepatitis C has killed more people than HIV, but I don't think they knew that would happen at the time H was told.

13. Before we knew about the HIV, in around June 1983 I was pregnant. I was only 17 years old and very impressionable. We were called in to see Professor Bloom who wanted me to have a termination. He was very insistent and said that there was a good chance my child could likely have Haemophilia. But I kept the baby, and when GRO-B was born in GRO-B 1983, they took blood off him and told me that they were testing him for Haemophilia, but I now think he could also have been tested for HIV.

14. I now know that Professor Bloom told H sister-in-law, GRO-B that Haemophilia stopped with males and so I now believe that Professor Bloom wanted me to terminate my child due to H having HIV and or Non A Non B Hepatitis, and that this was what they were testing my child for when he was born; not Haemophilia. I did not get the termination but I have since worked this all out. I always wondered about his real reasons, as he was quite insistent about a termination.

15. When my son was around 18 months old, I fell pregnant again. I had been told that due to all the risks around at the time, any more children I had were guaranteed to be infected, as would I. Due to fear I therefore decided to get a

termination and I regret that to this day. It was, and still is, heart-breaking to see other couples with multiple children and I used to breakdown when I saw other children.

16. I never wanted to get a termination. It makes me so angry about it just thinking back to the appointment with Professor Bloom before GRO-B was born and the information he gave us about having children. I did not even tell my parents about the termination. It is heart-breaking as I wanted a big family and other infected people have gone on to have other children.

17. As we were told we could not have any more children, H and I decided to adopt. When we started looking into adoption in or around 1994 we were told that we could not adopt due to H HIV status. The Head of the Adoption Service said that there would be no chance. I don't give up easily and so I wrote to her boss, who was someone higher up in the decision making process and explained that we already had a child. I caused such a fuss that eventually after about 2½ years they finally accepted us and we passed our Adoption Preparation Course. GRO-B GRO-B GRO-B

18. We adopted a girl in around 1997 and then tried to adopt 2 children when H was ill with Hepatitis C treatment side effects but we could not cope with them. We then adopted our daughter in 2016.

19. Further details of my husband's infection are listed in his witness statement to the Inquiry.

Section 3. Other Infections

20. In 1995 he received a letter about vCJD, informing him that he had been exposed to the disease.

Section 4. Consent

21. I believe that H was treated and tested without his knowledge and without being given full information.

22. I do not know if my husband ever gave his consent to being treated or tested for either HIV or Hepatitis, however, I am aware that he was put on the experimental, unlicensed Hepatitis C treatment of Interferon and Ribavirin although I cannot remember the year. I believe that this must have been for research purposes.

Section 5. Impact of the Infection

23. H was fine for a long time and did not suffer from any mental or physical effects. When B started to get ill in or around 1988 or 1989 though H prepared himself to get ill. He did not think anything mattered anymore; and would always say "*I'll be dead soon*". He did not seem to care about things.

24. When B passed away in GRO-B 1992 H went off the wall and began to drink excessively. When he was given the AZT treatment on a trial at the same time as his brother B we were told that some people would be on a placebo and some would get the treatment. H always felt a lot of guilt as we later found out when B died that he had been given the AZT treatment and his brother was given the placebo. He did not think it was fair as he did not even take the pills religiously like B

25. He then developed PCP pneumonia in 1993 and was given just a few weeks to survive. He did not want to see anyone and did not want to leave the house and risk them finding out. We moved home to get away from everyone because when he developed pneumonia we thought people would guess he had HIV. We both therefore lost contact with all our friends. Especially as this was after B had died so H assumed everyone would guess and assume things.

26. H suffered from his body weakening, significant weight loss, constant mood swings and not being able to sit out in the sun due to being on the drug Septrin.

27. He was given AZT treatment, then other drugs, but nothing was licensed. He was just asked if he wanted to try a new drug and whenever he was asked, he always said yes. He would then try a drug for about 6/8 months and then would just change it if it did not work, having check ups every 6 weeks.

28. In 2002 H had pancreatitis due to his Hepatitis C treatment of Interferon and Ribavirin. This, with the combination of his HIV treatment AZT, sent him into the ICU unit in hospital. He stopped taking all treatments. He had been on Hepatitis C treatment for about 16 weeks and had cleared it; however the virus then came back after he had stopped the treatment. He was given a lot of fluids and had to just ride out the pancreatitis. He was not treated very well in the hospital and even when they tried to attach a cannula they were digging into his arm and I had to get annoyed as they could not find a vein. They did not take much care.

29. A few years later H had a second lot of treatment for Hepatitis C, consisting of just the tablet (Ribavirin), which was not as bad. He had this for about 6 months and again cleared the virus before it came back just 3 weeks later.

30. In 2017 he was given Harvoni and after 3 months he cleared the Hepatitis C infection.

31. H always told the hospital that if any treatment was available then he would have it. When he was told about the Harvoni treatment, he was put on a waiting list for it due to funding issues. As soon as he was offered it though he took it up.

32. Hepatitis C did not really affect his liver. A fibro-scan that showed it was fine. They monitor his liver with these fibro-scans every year.

33. While he was on the treatments H suffered mental and physical effects such as always feeling sick, diarrhoea and weight loss. He was not taking all his tablets though so I do not know if the side effects were lessened due to this. Each set of tablets had their own side effects.

34. H was constantly aggressive and just angry at life. Dr Dasani told me that we might want to move into a hotel. He hated food and lost his appetite completely.

35. H and I were trying to adopt children at the time and so GRO-B had to go back due to H condition. He just did not want them to be around. He was always angry and directed it at anyone around him.

36. I am not aware of H suffering any side effects from the Harvoni treatment.

37. He always had to see the hospital dentist due to his conditions, and was told that his teeth were crumbling due to the infections he had.

38. Neither H nor I ever told anyone that he had HIV or Hepatitis C. We eventually told my parents after H had been suffering from the infections for a while.

39. As I said earlier, we were a well known family in our area and so in around September 2001 we moved away from everyone and cut them off as we could not deal with the constant questions. People knew H was a Haemophiliac and so that would lead to more probing questions. We now have different friends who do not know anything about all this.

40. H almost became a recluse and was so closed off due to being worried about stigma. We felt so isolated.

41. My husband's infections had a large effect on my work. I started a GRO-B shop in around 1995 with a fund of about £5,000. I rented a shop and within about 2 to 4 years I built up a very successful business and at the end had 4 girls working there. The income from the shop paid our mortgage off and the business became VAT registered. When H was well, he would deliver GRO-B within a 20 mile radius. However, I had to sell to sell this in around 2003 because H became so ill and because of everything that was going on.

42. After selling the shop I had to change career and studied for a Social Work degree and did a dissertation on Contaminated Blood in 2007, looking at when the Factor VIII could have been heat treated. My supervisor suggested that that I could have continued my research and completed a Masters, however, I was so shocked by what I found I could not go on. I have 2 copies of my dissertation.

43. I started working for the Council in around 2008 as a GRO-B GRO-B but I had to take time off when H was ill. I have had to change and adapt my plans all the way along.

44. We have not been on holiday for years. I am now self employed so can work from my house and am qualified in alternative therapies and healing.

45. We only told our son about H infections when he turned 18.

46. Every time I tried to deposit money into the bank I was asked to explain where the money was coming from. The bank manager said it could be drugs related, even for the monthly payments. It was humiliating and I refused to answer the questions from Lloyd's Bank. They were horrible and rude and as they refused to let it go, so we moved banks.

Section 6. Treatment/care/support

47. Apart from waiting a few months on the waiting list for Harvoni, I do not think H ever really suffered any obstacles to treatment.

48. I have never been offered any counselling or support but I believe both H and I would have benefited from having some. At the very least it should have come when we were told about his HIV infection. We have had serious bad patches financially and emotionally.

Section 7. Financial Assistance

49. We found out about financial assistance from the Birchgrove Group and the 1991 litigation. H received about £60,000 from the MacFarlane Trust. Both H and his brother B were told to sign the waiver or no one would get a pay-out, however, they knew people that were receiving the money already and so they refused to sign.

50. He also receives monthly payments from the MacFarlane Trust. It used to be around £600 but then increased to around £1,200. Now the payments come form EIBSS and they were at £1,500 a month, but have been temporarily increased to around £2,200 by the Welsh government as they have honoured the extra means tested payment for everyone; however they did say that it can end at any time and reduce to £1,500 per month.

51. He also received US$20,000 from the American litigation.

52. H also received a £25,000 Stage 1 lump sum payment from the Skipton Fund. Initially he was refused before the criteria changed and he was then accepted.

53. The MacFarlane Trust was never fit for purpose at all. Even when we have been in dire streets and desperately needed help, it felt like begging. We did not want to go begging to them as they always just said no anyway and so did not apply. Even now we do not have a downstairs bathroom.

54. The trusts were very poor and made the process of getting money very long and difficult. I hated the Skipton Fund and the MacFarlane Trust. They always acted as if the money was coming straight out of their pockets. They would

send us letters telling us to apply for a grant from the social care fund from our local council before we applied to them for financial assistance. They allowed us no dignity and really made us beg for the funds.

Section 8. Other Issues

55. The Birchgrove Group gave us all a voice.

56. I understand that Professor Bloom died a few years ago. He had the final word in Cardiff and there was no one higher up in Cardiff. Balancing the finances of the hospital as well as the care of patients aged him considerably.

57. Due to the Public Inquiry there is currently a discussion at the hospital about whether to change the name from the Arthur Bloom Haemophilia Centre, but he did a lot of work there.

Anonymity

58. I would like to be anonymous.

59. I would like to provide oral evidence provided that it could be given on a private and anonymous basis.

Statement of Truth

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

Signed. **GRO-B** ......

Dated........9 May 2019........