

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1770001

Exhibits: 0

Dated: 26 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:-

Section 1. Introduction

GRO-B

2. I make this statement as the daughter of **GRO-B**
GRO-B and who was infected with HIV and Hepatitis C, as a result of being treated with contaminated blood products.
3. **This witness statement has been prepared without the benefit of access to my fathers medical records.**

Section 2. How infected

4. My late father was diagnosed with severe Haemophilia A, with less than 0.01% clotting factor. He was diagnosed as a child, at the Royal Victoria Hospital (RVH) in Belfast. I am not aware of the specific circumstances of the diagnosis.

ANONYMOUS

5. I am not aware what my GRO-B was treated with as a young child. I believe that he started receiving Factor VIII in the 1970s as he started receiving it from when it first became available.
6. My GRO-B was treated with Factor VIII his entire life. I do not know the specific brands or batch numbers of the blood products that he was treated with. I have attempted to obtain his medical records; from RVH however, I have been informed that they have been destroyed.
7. From about the 1970's my father received his treatment at the RVH, under the care of Doctor Elizabeth Mayne the Consultant Haematologist. I do not know who his consultant was before then.
8. I am aware that Doctor Mayne retired not long before my father passed away. I believe that he was under Doctor McNaulty, specialist registrar at the time he died.
9. My mother told me that, when they were on a holiday in Spain in 1982/83, she read an article in a Majorcan newspaper which was in English. The article stated that blood products were contaminated. Upon their return to Belfast, my mother brought the newspaper to Doctor Mayne and raised her concerns. Doctor Mayne responded that the blood products were safe and my mother was scaremongering. My GRO-B was really concerned for the other haemophiliacs, (whilst not knowing that he was, in fact, infected himself.) GRO-B was infected in or about 1981; however, GRO-B was not informed about it until 1986.
10. I consider it unlikely that my father or his parents was given any information or advice about the risk of being exposed to infection from blood products before being treated as he would have mentioned it.
11. In 1986, a group of 12 haemophiliacs (including my father) were invited to a meeting with Doctor Mayne and were told at the group meeting that they had been infected with HIV. They were never given any indication as to the reason for the meeting before it took place. After this news my parents were

ANONYMOUS

concerned as my sister had been born in 1981, so her and our mother had to be tested. Thankfully, neither of them was infected.

12. I do not think that they were given much information if any about how to manage their infection, or what it actually meant for them in a practical sense. There was no adequate information provided or moral support.

13. I believe that my **GRO-B** should have informed about any infections he had when the doctors first found out about them.

14. I believe that a way in which my **GRO-B** and the other haemophiliacs present in the meeting were informed about their infected status was inappropriate and unacceptable. This should have been done in private.

15. My **GRO-B** was informed about being HCV positive in the 1990s. He was asked to attend the hospital for a routine check-up and at that appointment was told he was HCV positive.

16. I do not think that there was much, if any, information provided about his infection or how to manage it or about the risk of others being infected, in that initial meeting.

17. The manner in which the meeting took place was very clinical and cold and I do not believe that it was appropriate.

Section 3. Other Infections

18. As far as I am aware, my **GRO-B** did not have any other infections.

19. I am aware that there were letters sent around informing other haemophiliacs about being exposed to vCJD; however, I believe that as my father had passed away before then, we did not receive one.

Section 4. Consent

20. I believe my **GRO-B** was treated and tested without his knowledge, consent, or being given adequate or full information as he didn't know he had been tested for HIV and HCV before being told the test results. I have since become

ANONYMOUS

aware that all my family were tested for HIV in 1986 without our knowledge or consent.

21. I am not aware as to any specific information about my GRO-B being tested for research purposes; however, I believe that he might have been.

Section 5. Impact

22. After my GRO-B was given his diagnosis he became very depressed, grumpy and angry. He was constantly down. He also began to drink. Before the diagnosis He only drank occasionally. However, ever since he found out that he was HIV positive, his drinking increased significantly.

23. I believe that my GRO-B found it very hard to cope with the thought of having such serious viruses. He was never offered any mental health support or counselling to help him to deal with them. In fact, none of us were ever offered support or counselling.

24. We never felt like we could be open with people about his illnesses. There was a massive stigma attached back then, and we were afraid that people would turn away from us if they knew.

25. We did have a few family friends turn away from us. When they found out about his illnesses, they would gradually stop visiting us, and would not bring their children over to play with us, and eventually all invitations dried up. We found it very hard to deal with, and we felt very isolated.

26. My GRO-B illnesses also affected his work and our financial situation. When he became very unwell, he had to give up work. This was around four or five years before he died (around 1993/4). He was hardly able to get up, he was very yellow and jaundiced, and he generally looked very ill.

27. My GRO-B was put on the Interferon treatment in or about 1992/3, which caused big sores all over his body. As a result of this, he lost all his confidence. The Interferon treatment made him even more depressed; he was sick, had awful headaches and lost a lot of weight. Unfortunately, the

treatment did not prove to be successful. He continued with the treatment until he was no longer able to.

28. I do not think that he was given any other treatment.

29. My GRO-B had health complications as a result of the viruses and/or the treatment taken in particular a major issue with his liver, as a direct result of his HCV.

30. In or about the 1990's my father was treated with AZT for his HIV. However eventually the HIV developed into AIDS. We all knew that my father did not have a long time to live, but he went down a lot more quickly than expected.

31. In 1994, my GRO-B had a knee replacement surgery, which caused him to develop PCP (an infection caused by fungus). Since my father's immune system was so weak, we were not sure whether he was going to make it. Fortunately, he did make it. However, he never fully recovered.

32. In early 2000, my GRO-B developed Non-Hodgins Lymphoma due to his AIDS. He never knew about it, but my GRO-B and I were aware of it. Around three weeks before my GRO-B death, he was given an IV filled with green luminous liquid. I believe it was the treatment for his Non-Hodgins Lymphoma. We thought that he had a bit more time; however, around three weeks later his health deteriorated rapidly and he passed away, drowning in his own blood. It was horrendous the blood came out of his ears, eyes and mouth. I helped my mother look after him and we sent my younger brother and sister home until it was time to say goodbye.

33. One of the uncomfortable situations which my GRO-B had to go through as a direct result of his infections was that when he had his knee replacement surgery, instead of being put into the ward he was put into a side-room and then taken to the theatre. The surgeon came out wearing something which I can only describe as a biohazard suit; however, he eventually apologised for it.

ANONYMOUS

34. Regardless of how much he was suffering as a result of the Haemophilia the viruses, and treatment, my **GRO-B** tried to give my sister and I a normal life and childhood in those difficult circumstances.
35. As mentioned above, we had quickly learned that his infections were something not to be discussed with other people, as we would not get any sympathy for it.
36. My parents were both very social people before my **GRO-B** was infected but afterwards they became quite withdrawn. They did not go out, and became introverted and their group of friends was very small.
37. It was an extremely difficult time for us. In the 80s there were TV adverts about HIV with tombstones and AIDS. It was scary and hard to watch. I recall hearing people telling jokes about AIDS and HIV, and although they were upsetting and hurtful we were not able to show that we were upset and hurt.
38. Eventually we had some support from the people that we would not expect it from; our neighbours and the gay community. There was a lot of prejudice at the time around the gay community, but they proved to be a great support, particularly for my mother.
39. There was the Rainbow Project that my **GRO-B** was a part of. They organised a number of different events that she could go to and have a bit of a break. She always had someone to talk to there, and they did relaxing activities such as aromatherapy massages. I think that this was a nice getaway for my mother. However, this was something that she had to find herself; it was never offered by anyone.
40. There was also quite a lot of pressure put on me by this situation. I had two younger siblings and whenever our father was not well, which was often, I would pick them up from school and look after protect them.
41. Around the time when my **GRO-B** was very unwell, his condition was very hard to see as he was spitting and vomiting blood so there was blood everywhere. I felt like I had to protect my siblings, but at the same time, we all wanted to

ANONYMOUS

have the chance to say goodbye. This was an extremely traumatic experience for all of us.

42. My mother was also affected badly; she still is. After **GRO-B** died, she lost all hope. Our **GRO-B** was our main source of income, so we were also in a very difficult financial situation. She got very depressed and took an overdose of drugs; she was eventually referred to counselling, as she clearly could not deal with our father's death. My **GRO-B** has never been the same since my father passed away.

43. At the time we did not have enough income to pay the mortgage on our family home, so we lost it and had to find somewhere else to rent. My grandfather gave us £400 for the deposit and helped us for about a year.

44. When our mother was very unwell, she stayed with our grandfather. The responsibility of looking after our family fell on me. My income supported the whole family. It was extremely difficult. I was a single mother of an 18 month old at the time. I had to look after my brother, sister, daughter, mother, myself and the house. I was 22 when our father passed away, and I had a lot to take on all at once.

45. We were not entitled to any benefits at the time, other than the child benefit I received for my daughter. My mother was also too young to be entitled to pension payments as a widow.

46. My mother knew that my **GRO-B** was very ill and that he was going to die. She was trying to save up, but he went very fast. My **GRO-B** was never able to obtain life insurance, because of his HIV and any help that he originally received ended on his death.

47. My **GRO-B** illnesses affected my education as I was not inclined to work hard at school, because I was aware that I had to stay at home and help my mother. Losing my father was an extremely difficult experience; however, on top of that we also lost our home and lifestyle. This tore us apart, as a family.

48. This experience had caused me great trauma. My son has Haemophilia classed as severe. I was able to handle it until he had to start receiving Factor VIII. I was very worried that the same thing would happen to him as I had completely lost all the trust that I had for doctors. This also made me realise that I had never really dealt with my GRO-B death and the cause of it. As a result of all the stress my mother developed Hypertrophic Cardiomyopathy (HCM) and high blood pressure, which she is dealing with to this day.

49. I have to live my life knowing that my GRO-B will never experience many of the things that he should have experienced. He was a grandfather to my daughter for a very short period of time, but he was not able to watch her grow up, and he was not able to meet his grandson.

50. It is upsetting to me, knowing that my son has the same condition as my father, who if he was alive could have given him the support and understanding that we are not able to give him.

Section 6. Treatment/Care/Support

51. I do not think that my GRO-B had a difficulty accessing treatment, as a result of being infected with HIV and HCV.

52. None of us were ever offered any counselling or psychological support, which I believe would have been very helpful for all of us.

53. Around two years after my GRO-B death I started having panic attacks and anxiety. This is when I first received counselling; however, this was through my GP and employer, not the state. This was notwithstanding the fact that the panic attacks and anxiety were a direct result of my father's death and the stress caused by it.

Section 7. Financial Assistance

54. I believe that my GRO-B might have received something from the MacFarlane Trust, but I do not think that he had received anything from the Skipton Fund.

ANONYMOUS

I am not aware as to any specific dates or amount of financial help. I was never told of any trusts or funds.

55. I believe that my GRO-B is in receipt of some payments now, but I am not aware of any details.

56. I am not aware about the process of applying for any financial help or support.

Section 8. Other Issues

57. I am very disappointed with the response of the Haemophilia Society. I feel whilst some things have changed and improved, they haven't changed enough. Since my son is a haemophiliac, I still have contact with the Haemophilia Society, and unfortunately I have become aware that they are still not releasing all the information that they hold.

58. I really wish for some justice for my GRO-B and I hope that this Inquiry will help to achieve it. I believe that an apology would be worthless, as my father is no longer around and this would not bring him back.

59. I hope that the people who allowed this awful tragedy to take place be held accountable and to be prosecuted for their actions and that nothing like this will ever happen ever again.

60. I also think that the people who are still around and have been affected by the tragedy should be supported by the government throughout their lives.

61. I do not want any other family to endure the same issues we had to when my father died. No-one should have to lose their home as we did due to being infected with contaminated blood.

Anonymity, disclosure, and redaction

62. I wish to be anonymous and do not wish to give evidence

Statement of Truth

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

Signed...

GRO-B

Dated... 25/4/19...