Witness Name: Valeria Edna Sanders
Statement No: WITN1504001
Exhibits:0
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF VALERIA EDNA SANDERS

I, Valeria Edna Sanders will say as follows:-

Introduction

1. My name is Valeria Edna Sanders. My date of birth is GRO-C 1942 and I am 76 years old.

2. I live at GRO-C Staffordshire. I live here alone. I retired when I was 67, but I use to work for the NHS in administration which I very much enjoyed.

3. I make this statement on behalf of my late son Ian Robert Mather (his previous surname was Share), who was born on GRO-C 1968 and sadly died on 22 February 1994. Ian was infected with HIV and Hepatitis C (HCV) as a result of receiving contaminated Factor VIII treatment.

How infected

4. Ian suffered from severe haemophilia A and he had a clotting factor of 0.5%. Ian was diagnosed with haemophilia in 1969 on his first birthday when he fell over and cut his cheek.

5. I have four brothers who are haemophiliacs as my mother was a carrier, I am also a carrier, so I always knew there was a chance Ian would be a haemophiliac. Prior to Ian's diagnosis, I started to notice bruises on parts of his body, mainly his ankles, so I decided to take him to the baby clinic for a check-up. I expressed my concerns but these were ignored, instead, I was accused of abusing my baby. I kept repeating that there was every possibility he was a haemophiliac, but the doctor was not listening. He said if there were any more signs of 'abuse', he would report me. This made me very upset as I did not want people to think I would ever abuse my baby.

6. Ian was diagnosed with haemophilia A at Birmingham Children's Hospital under the care of Dr GRO-D. He started cryoprecipitate in 1969 and in 1977 his treatment was changed to Factor VIII (FVIII).

7. I was not provided adequate information about the FVIII, nor was I informed of the possible side effects or that it was a trial. I was just advised that Ian's treatment would be changing from cryoprecipitate, to a 'wonder drug' called FVIII. I simply trusted Dr GRO-D advice as he was my son's doctor.

8. Growing up was not easy for Ian. He had to attend a special school from the age of 4 and he often took long periods of sicknesses due to bleeds. He enjoyed running and cooking but he was unable to take part in any contact sport.

9. In around 1982, I started hearing rumours that the FVIII was coming from America, and that it was being provided from homeless people, prostitutes and drug addicts. I was very concerned about these rumours. Ian and I attended a 12 monthly health check and I asked if Ian had been infected by the Factor VIII. A nurse was also present during this appointment. At first, Dr GRO-D said he could not tell me without Ian's permission (Ian was then aged 14), so I stated that Ian is still a child and he was under my care, so I had every right to know. Ian was present during this appointment and demanded Dr GRO-D tells us the truth. Dr GRO- turned around and looked at the nurse;

she said she was not sure if Ian had been infected as she did not have his notes to hand. However, the notes were on her lap. I kept pushing them to tell me the truth and in the end, I was informed that Ian had been infected with HIV when he was 9 years old but they decided not to tell us since they knew very little about HIV at the time. Ian looked at Dr GRO-D and said 'how dare you, my mum has splits in her fingers from injecting me with FVIII all these years, I could have infected her.' He was more worried about me than himself.

10. I was simply advised that nothing further could be done for Ian. I asked Dr GRO-D what he meant by this, and he said, "Ian only has another 5 years to live". I was shocked; I looked at Ian and I could see tears in his eyes. He was only a child, how do you expect a child to cope with such news? I still remember that day like it was yesterday.

11. With regard to the HCV, Ian was having awful nose bleeds and pains in his stomach; I made an appointment to see Dr GRO-D sometime is the mid 1980's. Dr GRO-D examined Ian and confirmed that Ian has been infected with non A/non B Hepatitis (now known as the HCV). I was told they suspected this in 1979 (when Ian was aged 11) but there was nothing they could have done about it as there was no treatment they could offer him.

Other Infections

12. I am not sure if Ian was infected with any other infections.

Consent

13. I believe Ian was tested without his knowledge and consent. He had blood tests all the time, however, we were never told what for, I just thought this was normal due to his haemophilia.

Impact of the Infection

14. In August 1993 Ian started loosing a lot of weight. When I questioned if he was ok he just said he was fine, he just 'did not want to eat.' Ian used to weigh about 10 stone but he dropped to as little as 4 stone just before he died.

15. Ian had a girlfriend at the time and he did not want her to see him so ill so I moved in to look after him. I slept on the floor of his apartment.

16. Dr GRO-D started Ian on AZT after I confronted him about Ian's HIV in 1982. Ian took the medication religiously from the age of 14 until he passed away at the age of 25. AZT had many side effects which were more apparent towards the end of Ian's life. These included vomiting, dizziness, weakness and muscle pain.

17. When Ian died, the HIV had lowered his immune system and the HCV attacked his liver. He was in the early stages of AIDS. The Wednesday before he died he went a dark yellow colour and his eyes went brown; Ian had jaundice. He stroked his tummy and said 'look mum, I'm putting on weight, I must be getting better'. I could not bring myself to tell him how he really looked and that his tummy was looking bigger due to his inflamed liver.

18. Ian was the best son anyone could have. He always had a smile on his face and he never complained because he never wanted to worry anyone. He lived for the moment and did everything to make the most of the present day. I tried to be brave when I was with Ian but I was terrified for him when he was diagnosed with HIV. I went through a stage of thinking it was all my fault because I knew there was a chance I might have a baby who was a haemophiliac. I wished I was suffering instead of Ian because I somewhat thought I deserved it. I could not help but blame myself for all his pain and suffering.

19. A few days before Ian died, I held him in my arms and we spoke about our time together for hours. I told him I was so sorry that I had him and that I put him through all this pain and suffering. He held my hand and said he was so

grateful that I gave him this life and that he did not want it any other way. He said I was the best mum anyone could have.

20. Ian did not want me to tell any of the family that he had been infected; I believe this was because of the stigma attached to HIV and the HCV. There was a time when it came on the news that haemophiliacs had HIV and that they were spreading the HIV virus. This made Ian very angry. He always felt that the media was doing everything to draw the attention away from the link between FVIII and HIV and the HCV.

21. I remember I had bought Ian a silver ingot engraved with his name and the fact that he was a haemophiliac. This was in case of emergencies. When he died I took the ingot off him, I saw that he tried to remove the haemophiliac part due to the association between haemophiliacs and HIV.

22. The stigma has affected me too. My former husband (not Ian's birth father) once had the flu and he told me I had given him AIDS. I told him I had not got AIDS myself so that was impossible. I did not tell people that Ian had been infected. It was only near the end of his life I told people he was terminally ill but did not specify why. It was very difficult having to keep his infections to myself and not being able to talk to anyone about it. I had to suffer in silence knowing I was going to lose my only child. On one occasion, I tried talking to Ian's birth father to tell him Ian was going to die and he said 'he couldn't do anything about it'. He did not attend Ian's funeral either. I separated from Ian's father when Ian was 4 years old.

23. Ian's infections have also had an impact on other loved ones in his life. Ian's girlfriend always looked sad when Ian was ill. She started drinking more and put on a couple of stone. I believe this was because she was worried about Ian and this was her way of coping with it all.

24. My four brothers refused the FVIII treatment when it first became available because they felt that they had not been provided with adequate information. As a result, they ended up living a normal life, but Ian did not. One of my

brothers was so upset that Ian was infected from the FVIII treatment, he kept saying it should have been him who died, not Ian. He was so distraught he could not bring himself to come to Ian's funeral.

25. Ian's haemophilia and his infections also had an impact on his work. Ian was a head chef, however, he lost a couple of his jobs because they found out he was a haemophiliac and may have HIV. His former employers informed him that it was too risky to have him in the kitchen.

Treatment/care/support

26. I have never been offered any counselling or support. This is something I would have benefited from as I had no one to talk to.

Financial Assistance

27. I was approached by the Queen Elizabeth Hospital in 2012. I received a phone call saying that they had been trying to contact me to pay me compensation for my son. I then received £20,000 from a fund.

28. When I filled in the application there was a list of 4 options which said you might be entitled to more, number 2 was HCV. It then took me 2 years to be provided with the extra money because they would not believe me when I said Ian had the HCV and died of cirrhosis of the liver. In the end, I said I would go to the news reporters and involve solicitors. Within 4 days my application was processed and I received a further £50,000 in 2014. I believe these payments were from the Skipton fund.

29. I believe Ian received at least £20,000 from the Macfarlane Trust. Margret Thatcher then said £20,000 was not enough so he was awarded another £22,000, so I believe Ian received £42,000 in total.

Other Issues

30. No one has ever said they are sorry. There has been no apology for taking my son's life. I am not doing this to get more money. You could give me millions of pounds and it will not bring me my son back. I just want someone to take responsibility for their actions because this has wrecked the lives of many innocent people.

Anonymity, disclosure and redaction

31. I confirm that I do not wish to apply for anonymity. I understand this statement will be published and disclosed as part of the Inquiry.

32. I am happy to give oral evidence if necessary.

Statement of Truth

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

Signed... GRO-C ....

Dated 24/01/2019.