

Witness Name: T L HEATON

Statement No: WITN3852001

Exhibits: 0

Dated: November 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TRACEY LOUISE HEATON

I, Tracey Louise Heaton, will say as follows:-

Section 1. Introduction

1. My name is Tracey Louise Heaton. I was born on GRO-C 1962. I am married and live at GRO-C.
2. I make this statement as an affected person and in relation to my brother Gary Norman Fitzpatrick who was born on GRO-C 1969 and died on GRO-C 1993, aged 22. He was infected with the Human Immunodeficiency Virus (HIV) through receipt of contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my late brother's medical records. I understand that my mother, Irene Fitzpatrick, has also given a statement to the Inquiry.

Section 2. How Affected

4. Gary suffered from Haemophilia A which was diagnosed when he was 5 months old. I have two younger sisters as well and so this was tough for Mum having four children under the age of 8. Our father GRO-D left the family for good when Gary was a teenager.
5. Gary was treated at Pendlebury Children's Hospital. We became very familiar with the hospital and we spent a lot of time there when Gary needed treatment for his Haemophilia. He was initially treated with cryoprecipitate to control his bleeds then, when Gary was about 8 or 9 years old, he was given Factor VIII concentrate. His consultant was Dr Evans.
6. In 1985 when Gary was 15 or 16 my mum received a letter out of the blue saying that Gary had been tested for, and was positive for, HIV.
7. We believe he was infected in or about 1985 when he had been hospitalised for a long period of time having broken his leg at school. He was given considerable amounts of Factor VIII concentrate at that time to manage the break. Unfortunately, because of his haemophilia, he was unable to wear a plaster cast and was placed in traction.

Section 3. Other Infections

8. I believe that Gary was also infected with Hepatitis but I am not aware of what type.

Section 4. Consent.

9. Neither my mum nor I (as Gary's older sister) were consulted about him being tested for HIV and as he was only a minor at the time I conclude that he was tested without consent.
10. He was not only tested for HIV without his consent or knowledge but we also found out years later that he had contracted Hepatitis. We were not advised of this and we do not know which type.

11. Accordingly, having regard to the above I can only assume that he was used for research purposes. My brother was involved in the AZT trial. I do not know if he signed anything for this but we believe he had the placebo and not the AZT drug. I feel this was a grotesque and very cruel way to use someone with his prognosis.

Section 5. Impact

12. At the time there was a lot of stigma and negative speculation about HIV in the press and on the news. Mum had been advised by the hospital not to tell the family, friends, Gary's GP or indeed his school.

13. Mum decided not to tell Gary but she did confide in me and my sisters. It was so hard keeping this from Gary but we did not wish to frighten him; he had enough to contend with as it was.

14. Mum was given no advice, help or support as to how to manage his infection at home and we were just left to get on with it.

15. A couple of years after his diagnosis Gary started having health problems. They started with a lot of chest infections and he was treated with inhalers and nebulizers. Gary found out about his HIV status at a hospital appointment when he was 18.

16. He was alone at the time and Mum did not know that he was going to be told this devastating news. He was frightened and scared and we only found out a few days later when he broke down and told Mum what had happened at the appointment.

17. I feel very strongly that this was a callous and cruel way to be told and was denied the chance of having someone with him to support him.

18. Gary's treatment was transferred to Manchester Royal Infirmary (MRI) when he became an adult and his main treating consultant was Dr Lucas.

19. He started to develop many more health issues as well as recurring chest and lung problems, skin conditions which included psoriasis and eczema. On top of all this he also had to deal with his Haemophilia.

20. Gary's mental health also started to deteriorate. He suffered from severe depression. He briefly left home to live with his girlfriend, [GRO-A] who he had known since school. [GRO-A] was also severely disabled with spinal muscular atrophy and Gary was her main carer at the time.
21. My sisters had left home to live with their partners and Gary became unable to care for [GRO-A] and himself at their flat so he returned home to live with Mum and me. [GRO-A] also returned to her parent's home.
22. Gary's mental health became worse and at times he had manic episodes. We later learnt that these were caused by the virus attacking his brain.
23. At one point Gary had an open wound on his ankle. An ambulance was called but they refused to take him unless Mum dressed it. She had to go to our local shop to buy a plastic bin bag to wrap his foot and leg in before they would transport him to hospital. Gary was certainly treated differently because of his infections.
24. We had very little advice, help or support over the years which I find astonishing. At the time we just had to get on with it. I remember that we did not even have a washing machine until towards the end of Gary's life. We received a small sum from a charity that our GP organised so that we could buy one.
25. Gary's GP, Dr Bolton, had been called in desperation one day by my mother. Gary's thrush in his mouth was so bad that Mum did not know what to do. I remember Mum pulling out clumps of stuff out of his mouth with her bare hands. When Dr Bolton arrived she asked outright if Gary had HIV. She was appalled at the state of him as the thrush was so severe it was all the way down his oesophagus.
26. We made our living room more like a bedroom for Gary as by now he was bedridden and unable to walk. He had to endure the embarrassment of Mum, myself (and other family members when around) to get him out of bed and on to a commode as he was too weak to use the upstairs bathroom.
27. A couple of weeks before Gary died he was craving something to taste. As the thrush in his mouth was so bad he had lost his sense of taste and craved anything spicy. My sister had

a car and drove into Manchester, [GRO-C] miles away, to get him a spicy meal from his favourite restaurant.

28. He ate some of it but then proceeded to vomit it all back. Mum and I cleaned him up. He then turned to Mum and said "that's it now, isn't it?". He knew that it was only a matter of time before he died.

29. He went on to say "Tracey will save me, she always saves me". How could I?

30. That was the last time he had any food or medication; he was too weak to inject himself and the district nurses would not or could not inject him.

31. Gary died at home on [GRO-C] 1993.

32. I remember Mum screaming [GRO-C] it was horrific. She did not want to live; she wanted to be with him but I think she only held back because of her daughters.

33. A few days later, men in white suits and gloves came to take away Gary's mattress. I do not know what our neighbours must have thought but we were past caring by this time.

34. Watching my brother die was horrendous. It is now 26 years since he died which is longer than he was alive. It is still so painful. I think it is made worse by the injustice of it all.

35. I still relive all the above and it has been very painful for me to put into words. I feel strongly however that our stories and that of our loved ones need to be told.

Section 6. Treatment/Care/Support

36. Gary did not have any counselling; we had no support.

Section 7. Financial Assistance

37. I am not aware of any financial assistance and would refer to my mother's statement in this regard.

Anonymity, disclosure and redaction

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

39. I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

GRO-C: T Heaton

Tracey Louise Heaton

Dated.....5/11/19.....