

Witness Name: Susan Margaret Gray

Statement No: WITN1248001

Exhibits: 0

Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN MARGARET GRAY

I, Susan Margaret Gray will say as follows:-

Introduction

1. My name is Susan Margaret Gray. I am the mother of Steven John Wood who sadly died on 16 February 1994 from HIV. Steven was 28 years old at the time of his death.
2. My date of birth is GRO-C 1948 and I am 70 years old.
3. I am a retired care assistant, currently living at GRO-C
GRO-C, with my husband who I married after Steven's passing.
I do not have any other children, Steven was my only child.
4. Unfortunately, my relationship with Steven's biological father came to an end whilst I was pregnant with Steven. Steven has never had any contact with his father.
5. This witness statement has been prepared without the benefit of access to Steven's full medical records.

How affected

6. Steven was born on GRO-C 1965. At 10 months old Steven had an accident at home and cut his finger on a shard of glass, this led to multiple tests and he was diagnosed with severe Haemophilia A at around 12 months old. There was no history of haemophilia in my family; I had not even heard of the condition until Steven was diagnosed. I am unsure whether Steven's biological father had a hereditary connection to haemophilia as I have had no contact with him since Steven was born.
7. Growing up was not easy for Steven, but he was a very active child from the age of 4, he enjoyed playing sports, however could not do so very often as he frequently bled from his knees. This was extremely frustrating and upsetting for Steven. The education authorities in Leeds suggested that Steven should attend a 'special school' due to his haemophilia, and he did so until the age of 16.
8. Each time he experienced bleeds, he was treated at St James hospital, Leeds, where he was under the care of Dr Swinburn. Steven initially received cryoprecipitate. I am not entirely sure when his treatment was changed to Factor VIII as this was not discussed with me. No information on Factor VIII, or the risks associated with the treatment was provided to me. As far as I was concerned, he was still receiving the cryoprecipitate treatment, and the only time I came to realise that he was being treated with Factor VIII was when it was too late. Unfortunately, as a result of receiving the Factor VIII, Steven was infected with HIV.
9. Steven did not have any symptoms prior to his diagnosis of HIV. Sometime in around the early 1980's, when Steven was around 18/19 years old, Dr Swinburn contacted him in order to be tested for a new disease but did not specify which one. He had a blood test but was not informed what this was for.

10. I remember asking Steven whether anything was discussed during the appointment, he just shrugged his shoulders and said it seemed like a routine blood test. Three weeks had passed and we were still waiting to hear from Dr Swinburn, so I contacted the hospital myself to find out what was going on. I visited St James hospital and spoke to a woman named Pat. At first she was very friendly, however after checking Steven's blood test result, her face dropped and she told me that Steven must make an appointment to see the doctor urgently. A week later, Steven got in touch with the hospital and he was told that he was HIV positive.
11. Both Steven and I knew very little about HIV at the time, so, I made an appointment to see Dr Swinburn for more information. She was very little help and did not provide me with much further knowledge. We were merely advised that HIV was a disease transmitted through homosexuals and told of the importance of using condoms. Nothing further was discussed. I recall her providing Steven with lots of condoms after each hospital visit. There was very little support, help or explanation given regarding Steven's HIV infection.
12. Post diagnosis, Steven had constant flu-like symptoms, which seemed to get worse over time. He began to get thrush very frequently and also developed shingles. He had a sore mouth and was constantly coughing which irritated him a lot. Towards the end of his life, his health deteriorated rapidly; he stopped eating and lost a lot of weight.
13. I do not remember the name of the treatment Steven was given for his HIV. All I know is that he took a tablet each day which affected his white blood cell count and he needed frequent blood tests to regulate this.
14. I have now found out from the Haemophilia Society that Steven was also infected with Hepatitis C. In 2017 I joined the 'Tainted Blood Group' Facebook page and a lady called Sue directed me to Skipton Fund, who then directed me to the Haemophilia Society.

Other Infections

15. I am now aware that Steven was also infected with Hepatitis C as a result of the Factor VIII treatment. As I have mentioned above, I only found out after contacting Skipton Fund and the Haemophilia Society in around early 2017.

16. I had no knowledge that Steven was infected with Hepatitis C prior to this, nor was this mentioned during any of his hospital appointments with Dr Swinburn. I don't think Steven was aware of this himself.

Consent

17. I believe Steven did not know that he was being tested for HIV at the time. When he was tested for HIV, he was merely told that it was for a 'new disease' associated with haemophiliacs.

18. Steven did not consent to being tested for HIV nor was he given any information about why he was being tested.

19. I am unaware if Steven had any tests for clinical research.

Impact

20. Shortly after he was diagnosed with HIV, I noticed that Steven became very reserved and anti-social. He had just started working for the education department in Leeds which he very much enjoyed. He had to give up his job after 8 months due to his health. Steven was devastated about this since work was the only thing distracting him from his reality. After this he did not have a regular job.

21. Steven rarely discussed his emotions with me as he did not want to upset me. When he was 19 he told me that if he looked after himself well enough he

may be able to live for another 10 years. He was always positive about his health, but I could tell he was also worried at the same time.

22. Despite Steven not wanting to talk about his condition, our relationship did not change post diagnosis although we both were aware of the stigma attached to his HIV, which did put some strain on our relationship. Steven was very 'matter-of-fact' and rarely discussed his concerns with me regarding the stigma of his condition, regardless of this, the stigma was evident. We had to keep his diagnosis a secret as we were worried people would shun him and not want to be associated with him.

23. Steven had a girlfriend around the time he was diagnosed; however, their relationship soon broke down as a result. He was heart broken about this. Not only was he living with HIV, he had to let go of someone he deeply cared for and loved very much. As a mother, it was very difficult for me to see my only child go through all of this.

24. I struggled with not being able to talk to anyone about how I was feeling. I felt so helpless and confused, but I had no one to turn to. I had to hide my son's illness from my family and close friends which I found very difficult. There were many times I needed to vent and talk to someone about my son, but I could not. I was so scared that people would judge him and stop associating themselves with me and Steven. I eventually told my sister about his condition and she was very supportive.

25. Steven left home at the age of 18 with my support. After he was diagnosed I often cared for him at his flat, I was a part time care assistant at this time so I was able to provide the care he needed.

26. I think about Steven every day and feel very alone with my grief. Although my relationship with my husband is good, I am unable to talk to him as he does not share the same grief. I have lost my only child and I have to live with this for the rest of my life. I cannot explain in any words how heart breaking this is for a mother.

Treatment/Care/Support

27. Steven was not offered any counselling or psychologist support. I believe he would have benefited from talking to someone as he was in a very dark place following his diagnosis.

Financial Assistance

28. I believe Steven did receive some financial assistance but I am unable to recall from which Trust or Fund. He was given £600 on one occasion for a washing machine.

29. I also received £1000 from the Macfarlane Trust after Steven died for his funeral. I did not have to apply for this sum, it was automatically sent to me after Steven's death.

30. I am part of the 'Tainted Blood Group' on Facebook, here a woman called Sue posted about the Skipton trust. I applied for the compensation and I received £20,000 from Skipton trust. I had to fill out a few applications and send them back. The process of applying for this was not pleasant, but I did not have major difficulties.

Anonymity, disclosure and redaction

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

32. I would rather not be called to give oral evidence, however if I am required to do so, I would do so willingly.

Statement of Truth

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

Signed.....

GRO-C

Dated 20th December 2018