

Witness Name: Suzanne Orford

Statement No: WITN1444001

Exhibits: 1

Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUZANNE ORFORD

I, Suzanne Orford, will say as follows:-

Section 1. Introduction

1. My name is Suzanne Orford. My date of birth is GRO-C 1978. I live at GRO-C Ireland. I have been married to my husband Matthew for 14 years. We have two daughters aged 12 and 5 and a son, aged 7. I own my own crafts business, called The Dolly Tub.
2. I make this statement in relation to my mother, Sue Hollywood. She was born on GRO-C 1955 and died on GRO-C 2019, at the age of 63. She contracted HIV and Hepatitis C as a result of being treated with contaminated Factor VIII (FVIII) concentrate.
3. This witness statement has been prepared without the benefit of access to my mother's medical records.

Section 2. How infected

4. Growing up, my family consisted of my mother, father and older brother, Anthony McCulloch. Anthony was born on GRO-C 1976 and upon his birth my mother was diagnosed with haemophilia A.
5. When I was around six months old, we were involved in a car accident and GRO-C My parents' marriage quickly went from that of husband and wife, to patient and carer.
6. Consequently my parents divorced when I was three years old and I continued to live with my mother and brother, whilst my father moved out to live GRO-C As such, I was always very close to my mother.
7. My mother was a brilliant parent; she raised us like a "tiger mom," but still continued to care for my father. We were all so close, almost unhealthily so, and became quite clingy towards each other because the three of us were our own little family unit and only had each other, once my father moved out.
8. Following her diagnosis, my mother was treated at the Liverpool Royal Infirmary (LVI) between 1976 and 1999, as well as the Manchester Royal Infirmary (MRI) between the years 1999 and 2000.
9. Dr Hay was the main consultant in the Haemophilia Department at LVI. My mother was treated with FVIII concentrate products and I believe she was infected on one or more of the visits listed below:
 - (i) 1976 after the birth of my brother;
 - (ii) 1978 after she gave birth to me;
 - (iii) 1982 after an operation to treat pancreatic cancer;
 - (iv) 1985 after she had an ulcer removed from her stomach;
 - (v) 1980's (various dates) after dental treatments;
 - (vi) 1989/1990 after she underwent a hysterectomy.

10. There may have been other occasions when she was treated with FVIII concentrate products. All such visits should be set out in her medical records.
11. When Dr Hay moved to Manchester, (MRI) my mother also moved to this hospital so she could continue to be treated by this particular consultant.
12. In 1985, my mother received a letter from the Children's Hospital in Liverpool advising her that Anthony had tested positive for HIV. At the time, Anthony was only eight years old.
13. My mother must also have undergone tests at this hospital because only one week later, she was informed by telephone that she had also been infected with HIV. My mother told me that Sister GRO-D who broke the news to her by telephone, was both unsympathetic and insensitive.
14. Following these developments, Dr Martin of the Children's Hospital requested my mother came to see him at the hospital to discuss the results. At this consultation, he advised her not to say anything because HIV was receiving plenty of negative media coverage. I do not know whether this was to protect my mother and Anthony from possible abuse and attack from others or whether it was to cover up the hospital's errors for causing the infections.
15. He also told my mother that the hospital had the relevant batch numbers of the FVIII concentrate products used to treat her, but did not know which ones were contaminated. He confirmed the products used were imported from USA and were sourced by a pharmaceutical company called Armour.
16. He advised her that she and Anthony could have been infected at anytime between the years 1981 and 1985. My brother and I accompanied our mother at this consultation and even though I was aged only six at the time, still remember the conversation that took place.
17. The general attitude of the doctors at this hospital was that of resignation. They believed my mother would die one year after testing positive for HIV. I

do not know whether or not there was any treatment for HIV in 1985 because my mother was never informed. I believe the doctors were waiting for her condition to deteriorate and die. The general approach of the hospital staff towards us was appalling.

18. It was not until 1990 that the doctors gave her tablets for HIV. I do not know when these tablets came onto the market and, if they were available earlier, why they waited until 1990 before offering these to her. The tablets were taken for six months but both my brother and mother stopped taking them because they were causing horrendous skin rashes. So far as I am aware, she was not given any other treatment to manage her infection.

19. My mother was about 30 years of age and must have been devastated to be told that her life was about to end. Anthony and I were very young and all of us were left extremely worried about our futures.

20. Initially, the doctors told us nothing about how to manage the infection. My mother was given no information or advice about what she should or should not do, to prevent spreading it to others. She was only told to keep quiet.

21. Sadly my brother died of AIDS about nine years ago, in 2010, at the age of 33.

Section 3. Other Infections

22. My mother was infected with HIV and Hepatitis C as a result of receiving contaminated blood products. She became aware of the HIV infection in 1985, but was never provided any information regarding her Hepatitis C infection.

23. My mother developed pulmonary fibrosis of the lungs and a number of other infections as her health deteriorated, eventually dying from a kidney infection. She also had heart disease but I do not know whether these were linked to her initial diagnosis.

Section 4. Consent

24. My mother knew she was receiving FVIII concentrate but was not made aware at the time of the risks of being treated with these products. She believed the products used to treat her were safe.
25. My mother was tested for HIV but this was done so without her knowledge or consent.
26. I do not know whether the doctors treated my mother for HIV when they first became aware of the infection. If they did, it was without her knowledge or consent.
27. I do not know when my mother was tested for Hepatitis C but this was done so without her knowledge or consent.
28. I do not know whether the doctors treated my mother for Hepatitis C when they first became aware of the infection. If they did, it was without her knowledge or consent.
29. I do not know whether my mother was tested or treated for the purposes of research.

Section 5. Impact

30. My mother died blaming herself for Anthony's HIV infection. There was nothing anyone could say to her to convince her otherwise. She used to say "he's dead now cause of me."
31. Her life was wasted and I blame the FVIII concentrate used to treat her. My mother became so ill and, in the end, had no quality of life. Her life should have been so different.
32. My mother had been depressed for several years. She had to deal with her own illness and yet find ways of coping with the loss of her son. She was always a very strong woman in her youth before the infection, but her mental

state gradually deteriorated, particularly after Anthony died. She was mentally tortured by the time of her death. It was horrible because she had always been the strongest person for us and it was sad that she never had anyone stronger around to be there for her.

33. It was difficult for me to see her like that because despite all that we had been through; my life was turning out okay. I graduated in 2001 and had taken a job as an artist in residence. I met my husband Matthew only a few weeks later, who was so understanding and so fantastic with all that was going on. However the fact that my mother was suffering meant I felt guilty for all the good things in my life; it was like a stabbing in my heart when I remembered my mother was never going to get a chance at a stable life ever again.
34. She herself grew complicated and I believe very much damaged. She wouldn't accept that none of this was her fault and additionally felt guilty when people in turn tried to help her to manage. The only person she accepted help from was me.
35. Anytime we had a good occasion she would turn to alcohol and hit the bottle, marring almost every occasion. I knew last Christmas would be her final one with us, so when she called completely drunk and adamant she wasn't going to come over to my house, I'd had enough and went to fetch her myself.
36. Physically, she had tubes in her nose connected to a concentrator in the house. Due to this, she was unable to walk around the house freely. She couldn't drive anymore so was merely surviving from one day to the next.
37. My mother often used to get pneumonia and had to be treated many times at the hospital. She was chronically ill and suffered numerous fractures on her spine. She had brittle bones disease, heart disease and skin cancers. I believe her medical state derived from being infected with HIV.
38. I believe it was about ten years ago when I assisted my mother with the Interferon injections with a view to clearing the Hepatitis C.

39. My mother did not face any difficulties or obstacles accessing treatment. She had always left her health in the hands of doctors. However, she was clearly let down by them all.
40. My mother had always been a very glamorous lady and having owned her own pub she was the life and soul of the party. She went from loving her life to not wanting to be alive anymore.
41. Physically I wasn't able to cope anymore. My father's sister came over to look after my mother to try and give me a break, whilst my friend took the children for a little while. My mother's condition worsened to the point where she became completely incontinent so we decided the best thing to do was to move her to a hospice where she could get better care.
42. On GRO-C 2019, my mother went to the hospice, but made it very clear she did not want to go. She laid down in the back seat of the car and grew more and more awkward, which I believe was due to the feeling she had that hospices were associated with death.
43. The next day however, she rang me in a better mood and to say that she was given a pint of Guinness the night before, which was something they regularly did there. In addition she told me the staff members were lovely and I began to receive happier texts from her in the mornings.
44. One morning she sent me a text message so I thought it best to visit her. The children and I were due to watch Dumbo in the cinema, so we thought we would pop in and see her first. When we got there, she didn't look in good health; she was hot and flushed and was battling the symptoms of a urinary tract infection. A doctor was called and attended to her an hour later. I asked the nurse if I should stay, to which she replied "your mother is a very sick woman."
45. At that point, I knew what was about to happen. I called for Matthew to come and collect the children, whilst my mother was moved to a beautiful room with a door opening up to a beautiful garden.

46. My mother's breathing became heavy; she sat up in her bed very quickly and began to take long gasps. This was when I was certain that this was it because Anthony breathed in exactly the same way just before he died. She almost flopped over on the bed, so I removed the tubes from her nose and held her in my arms whilst she took her dying breaths. I was heartbroken.
47. The next day, I was speaking with a funeral director who advised that due to my mother's infections, her body would have to be covered in a black powder, embalming would not be possible and her body put straight into a bag with the coffin closed shut.
48. Of course I protested but he, along with a number of other funeral directors, advised the same. I became so distressed and so desperate, my plan was to open up the coffin, wash her and get her ready properly before closing the coffin again and anyone could find out what I had done.
49. Eventually, I was put into contact with a funeral director by the name of Michael McGowan; who answered all my prayers and was truly a godsend. He said the process I had been advised of was not the law but people just did not want to touch her. He asked me to bring her body over to him and that he would help me make her up and as though she was still here. I would be able to kiss her goodbye and give her the send off she deserved. There was no way I would have let her go in just a body bag. It just feels as though Ireland is around 30 years behind in accepting those suffering with HIV and Hepatitis C.
50. My mother's funeral could not have gone any better. I sang at both her funeral and wake and it really felt like a true celebration of her life. Although the turnout was great, I have arranged for a party in Liverpool too because so many people couldn't make it to Ireland. A copy of the eulogy has been exhibited; **WITN1444002**.

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52. The stigma we suffered was horrendous. I recall when I was about seven years of age, I found out that Anthony was being bullied by other children at the school we both attended. They came to know through the media that haemophiliacs, drug users and gay people were all associated with HIV. They used to call him Rock Hudson. Anthony therefore never wanted anyone to find out.
53. We were terrified about how others would treat us and how this harassment would escalate. My attention turned away from my education and more towards fear.
54. I do not know which family members or friends knew about my mother's infection. All of us, a small family of three, tried to follow the advice given to us by Dr Martin because we were all scared about possible physical attacks on us.
55. Even in the hospice, my mother was paranoid about people finding out and didn't like that her room door had a red sticker to indicate her infection. I always remember her contemplating running away from her troubles. On numerous occasions I asked if she wanted to see a psychologist, but she just kept on refusing because of her diagnosis.

Section 6. Treatment/Care/Support

56. I do not know when the doctors first knew my mother had been infected with Hepatitis C. I believe the doctors initially advised my mother against being treated with Interferon because of her weak immune system.
57. In or around 2009, she started a course of Interferon for six months, but suffered badly from flu-like symptoms. Her general health suffered considerably during that period too. The doctors treating my mother for the HIV infection began giving her anti-retroviral tablets (combination therapy) but the doctors treating her for Hepatitis C objected to this because it was causing further damage to her liver, at a time when she already had cirrhosis. The

doctors seemed not to heed the advice of the liver specialists and continued giving her the tablets.

58. My mother was never offered support or proper medical advice. She should have received mental health treatment and general support. The hospital should have assisted her to cope with her infections caused by the doctors. I have been appalled at the hospital's attitude towards us, ever since my mother and my brother were infected.

59. I was never offered any form of psychological support either; however I did seek counselling following my brother's death which I felt was helpful at the time. My mother's passing feels too soon and too raw for me to seek help for just yet. I still need time to grieve for her properly, but will look to get help should I struggle.

Section 7. Financial Assistance

60. In the mid 1990's, The Macfarlane Trust paid my mother £60,000 for her diagnosis of the HIV infection.

61. She also received further payments; once in 2001 from The Skipton fund in the sum of £25,000 for Hepatitis C and once in 2007 for the sum of £25,000 for her liver cirrhosis.

62. My mother had to sign a waiver before each payment was made confirming she would not make any further claims if she received the money.

63. Additionally, The Macfarlane Trust used to pay my mother £1500 per month for the HIV infection and £1500 per month for the Hepatitis C virus. There were no obstacles or complications in obtaining either of these payments.

64. The Macfarlane Trust however did not release the money to Anthony initially and he only received payment when he turned 18 years of age.

65. I have never received any financial assistance. The only money I received was to go to Croatia with my family from the Macfarlane Trust. We all had to make an application to receive this payment.

Section 8. Other Issues

66. I have not had any involvement in previous litigation, despite my whole family having suffered enormously.

67. The Government needs to acknowledge what they did and that they knew about the products they were giving to people. It's terrible the process is going to take so long and people are dying in the meantime. Have they even accepted any of this? Even at this point, what are they up to?

68. Families need to be compensated for what they went through and although I've done well, not all families are in the same position. Nothing will bring back those who have died, but all this has gone on long enough now.

69. No money could ever compensate for the pain my mother suffered or all that she went through, but she always wanted a cottage by the sea and she should have that.

70. She should be here right now; out with her grandchildren, but instead she was 63 years old and died living the last of her days in fear. I'm still shocked that she's gone.

71. It used to be the three of us against the world and now a massive part of me is gone.

Anonymity, disclosure and redaction

72. I confirm I do not wish to remain anonymous and that I understand this statement will be published and disclosed as part of the Inquiry.

73. I wish to be called to give oral evidence.

Statement of Truth

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

Signed.....

GRO-C

Dated.....

23/9/19

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