

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2741001

Exhibits: WITN2741002-WITN2741007

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. GRO-B
GRO-B I am
married with a 5 year old son. I am a senior consultant for a technology firm.
2. I make this witness statement in relation to my mother GRO-B: M
GRO-B: M aged
50. She died as a result of liver cancer which she got as a result of being
infected with Hepatitis C from a blood transfusion in around 1986.
3. I exhibit at WITN2741002 a document from the Conquest Hospital detailing
my mother's past medical history and causes of death.
4. This witness statement has been prepared without the benefit of access to my
mother's full medical records. If and in so far as I have been provided with
limited records the relevant entries are set out as exhibits to my statement.

Section 2. How infected

5. My mother had a blood transfusion in around 1986, when I was about 3 years old. She required a blood transfusion because she had an ectopic pregnancy and her fallopian tube ruptured. This may have been at Hammersmith hospital because that was where I was born.
6. I am not sure which doctors treated my mum when she had the transfusion.
7. My mum was infected with Hepatitis C as a result of having the blood transfusion in 1986.
8. I do not know if my mum was warned about any risks before she had the blood transfusion.
9. I'm not aware of the detail of how my mum was informed of her infection, but my mum's sister told me that my Mum was told she had non A non B Hepatitis in around 1987.
10. I exhibit at WITN2741003 the results of my mother's tests for Hepatitis B and C from 1995, together with documents from my mother's medical records questioning the cause of her Hepatitis C infection.

Section 3. Other Infections

11. As far as I am aware, my mum did not receive any other infections as a result of her blood transfusion.

Section 4. Consent

12. I do not know if my mum was tested or treated without her consent.

Section 5. Impact of the Infection

13. I remember starting to notice that my mum had health problems when I was about 15 or 16 years old. I noticed that she was not as lively as she once was and was struggling more than she did when I was younger. She was constantly tired. The infection used to cause her legs and ankles to swell up, and she would turn yellow due to jaundice. She also got swollen glands.
14. I don't know whether she had concealed her symptoms up until that point. She had had a hard time in my earlier years, raising me on her own. I was a bit of a terror when I was younger.
15. My mum had multiple episodes of her liver problems causing varicose veins which went on to rupture. When this happened it looked like a murder scene. She would bleed and end up in intensive care. She also had numerous episodes of coughing up blood and being rushed to hospital by ambulance. It was awful, but she just had to deal with it. I exhibit at WITN2741004 some of the entries from my mother's medical records which record her attending hospital due to bleeding.
16. As a result of her Hepatitis C, my mum developed cirrhosis of the liver. A year or two before she died, my mum was diagnosed with liver cancer. She grew a 4.5 cm diameter tumour.
17. My Mum had a liver transplant at Kings College hospital 6 months before she passed away. This is what ultimately killed her, as the transplanted liver was badly rejected.
18. My mum died at the Conquest hospital in Hastings on GRO-B 2016.
19. My mum's main treatment was at the Chelsea and Westminster Hospital. My mum was trialled on different drugs. Her main treatment was Interferon. I can't

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remember when she started this, but I used to take her to the liver hospital for her to have it every two weeks. They also used to change the volume of her treatment.

20. Mum also had small doses of chemotherapy in tablet form, which caused her to lose her hair which really affected her confidence.

21. Interferon slightly reversed the effects of my Mum's Hepatitis C, but she was given it too late to save her.

22. I exhibit at WITN2741005 a letter dated 29.04.2011 detailing the treatment she was having at that time.

23. In terms of difficulties and obstacles in accessing treatment, access to the hospital was hard for us. There were only two specialist hospitals who could treat my Mum, Chelsea and Westminster and Kings College hospital, both of which are in London. As my mum lived in Sussex this made getting treatment difficult. My mum had to go to the hospital as they wouldn't send the treatment to her. This was difficult if she was unwell.

24. We used to have to drive 68 miles each way for every appointment. For each hospital visit, I would have to pay for petrol, the congestion charge and parking. Parking alone cost £12 to £16 a time.

25. I do not know if there was any other treatment that my mum should have been offered.

26. Interferon made my mum tired and she could not function after she'd had treatment. I remember my grandma coming over a lot to help my mum and look after her.

27. I remember my mum also suffering with sickness and diarrhoea when she was on Interferon, which changed the way she thought about food. It was

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hard on her body. I think she had to take other drugs to counteract some of the side effects. She was on a lot of medication before she died.

28. I remember my Mum mentioning something about her dental care being an issue with her Hepatitis C and it being difficult, but I don't know any more about this.

29. My mum told me years ago that one of the hardest parts of her infection for her was being a single parent and having to rely on me to care for her when she was unwell.

30. In terms of the impact of the infection on my Mum's life, the stigma attached to Hepatitis C was massive. My mum lost friends when she was diagnosed with Hepatitis C. Even now some of her friends still judge her. I bumped into one of her friends before she died and they asked me whether mum was still an alcoholic. This made me angry. People would just assume she was an alcoholic because she had Hepatitis C.

31. My mum was very outgoing when she was younger and she had lots of friends, but she only had one friend when she died.

32. The stigma even stretched to medical staff. I once overheard a nurse ask her how long she had been drinking for. When you say "Hepatitis C" people often wince.

33. I exhibit at WITN2741006 a letter my mother wrote to East Sussex Hospitals NHS Trust on 17th August 2009 complaining about the way she was being treated by medical staff because of the stigma associated with Hepatitis C.

34. I exhibit at WITN2741007 entries from my mother's medical records referring to her having an alcohol problem, which she strongly disputed, as can be seen from her letter of 17th August 2009.

35. My mum was seeing someone when I was about 14. He was around once when she had a bleeding episode and he couldn't cope with it. This caused them to split up, which really affected her confidence.

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36. Any stigma related to my mum's infection doesn't bother me now. Now I am older, I can articulate to people what happened to my mum and they understand. I can deal with it better now that she is not here.
37. What happened to my mum had a big impact on her sister. She was diagnosed with a mental illness (schizophrenia I believe) in the early 90's and she has spent much of her life in and out of hospital due to her mental health. When my mum was well enough she looked after my auntie. My auntie got better for 2 or 3 years, with support from my mum and was ok for a while. However, when my mum got ill, my auntie started relapsing.
38. I once took my auntie to Kings College hospital to see my mum and it affected her badly. My auntie refused to see my mum after that. When my mum died, my auntie's mental health deteriorated significantly. She went into a halfway house. She had two children, one was put in care and one looked after her. Within 3 months of my mum dying my auntie went back into a psychiatric hospital full time.
39. My mum's dad is still alive and lives in Malta, as do a lot of our family. He used to go to a lot of hospital appointments with my mum.
40. Before she became too ill to work, my mum was a fully qualified security guard. She said that this was the only job she could do where she wouldn't be asked about her medical history. She also used to volunteer in a museum.
41. My mum was clever. She did an Open University course in Art history, but didn't get to complete this because of her health problems. What she could have been capable of if she hadn't been ill was staggering.
42. My mum had to stop working as there came a point when she was not well enough to carry on. She then had to live off of disability benefits. Her standard of living was pretty poor. She couldn't afford to have a stable diet but she made the best of a bad situation.

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43. I remember my mum's applications for benefits being rejected a lot, as her condition was not recognised as being something which could make her too unwell to work.
44. My mum arranged her own funeral.
45. My mum meant the world to me. My mum was a single parent and brought me up on her own, so as well as being my mum, she was also my dad. My dad died of a heroin overdose when I was young.
46. To see someone as strong as my mum go through everything she did was tough. I remember going to the hospital with her a lot. It was frightening as a teenager. I became her carer when she was unwell.
47. My mum being infected with Hepatitis C had a big impact on my career. My mum was a proud woman and did not want everyone to know she was infected and to be branded an alcoholic or junkie. As a result, I had to provide employers with various excuses for why I needed a day off if I needed to take my mum to a hospital appointment.
48. My mum's hospital appointments would be a whole day off work. We had to travel from Sussex to London and my mum would normally need to be at the hospital for quite a long time for each appointment.
49. I lost a job at a big publishers because of the amount of time I had off work. I had been there for a year. I gave employers various excuses as to why I needed days off work, such as saying that I was ill or that my mum was ill, without going against my Mum's wishes. However, on that occasion, my employer said that they didn't think my heart was in the job.
50. Losing my job had a massive financial impact on me. I had to rely on my wife financially before I found another job, which affected our relationship.

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51. My mum's infections also affected my social life. There were times when I was out with my friends and I got calls to say that my Mum had been rushed to hospital. I used to have to drop what I was doing and sober myself up after a couple of drinks to go and be with her.

Section 6. Treatment/care/support

52. Counselling or psychological support has never been offered to me to help me with what happened to my mum. I don't know if such support was offered to my mum, but I don't think it was.

Section 7. Financial Assistance

53. My mum received a couple of payments from the Caxton Foundation and the Skipton fund. I believe she received £60,000 in total. I think one was in 1999 and another just before she died.

54. I believe she also received monthly payments of around £1,000 in financial support from one of the funds. However, this was not enough for her to live off and cover the cost of her attending hospital appointments. The lack of financial support she received was atrocious given that the infected blood scandal was so high profile. My mum barely lived day to day. My mum read stories about infected people in Ireland receiving so much more financial support than those in the UK and that was really tough on her.

55. Caxton gave me around £2,000 by way of a contribution towards my Mum's funeral. I have not received anything else from any of the Trusts or Funds in terms of financial assistance.

56. I didn't know much about the various Trusts and Funds until I met someone who was on one of the Boards.

Section 8. Other Issues

57. My mum wanted her story to be heard, so I am making this statement and participating in the Inquiry in order to seek justice for my mum.

Anonymity, disclosure and redaction

58. As my mum didn't want people to know about her infection, I will respect her wishes and opt to be anonymous.

59. I would be prepared to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-B ..

Dated 26/03/19