

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN3225001

Exhibits: 5

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:-

Section 1. Introduction

1. My name is **GRO-B**. I was born on **GRO-B** 1969. I live at **GRO-B** **GRO-B**. I am married and have two children, aged **GRO-B**. I currently work as a **GRO-B** **GRO-B** with my husband.
2. My father **GRO-B: F** was born on **GRO-B** 1943 and died on **GRO-B** **GRO-B** 2019 after being infected with Hepatitis C through contaminated blood products. He provided his own statement to the Inquiry prior to his death, under Statement No **GRO-B**.
3. My mother, **GRO-B** and sister **GRO-B** have also provided witness statements to the Inquiry. Their statements can be found under statement no. **GRO-B** and **GRO-B**.
4. This witness statement has been prepared without the benefit of access to my late father's full medical records. If and in so far as I have been

provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. Following a football injury to his kidneys, my father attended a hospital in Oxford with his uncle and cousin and was diagnosed with mild haemophilia A, at the age of 19.
6. My father's haemophilia was so mild that as a child I didn't even realise he had it. He mentioned an old ankle injury when playing sport but it only seemed to cause slight discomfort at times; it was nothing significant. Apart from that he was completely fit and well.
7. My earliest recollection of my father was a strong, sporty, intelligent man. He was very social and had a lot of friends. He was passionate about sport and was a wonderful father. He was supportive and really made me feel loved and safe. He was the sort of father you wouldn't hesitate to turn to if you needed anything and was the one person I could always trust to give fair and honest judgement.
8. My father was a very likeable man and this, along with his intelligence and skill set, took him on a path of successful careers. He worked extremely hard and as children we had enjoyable holidays abroad, fun on our boat and summer breaks at our beach hut in GRO-B I remember at weekends the local sports centre became our second home as my father was a competitive sportsman and a member of the GRO-B team alongside my mother. My parents were inseparable.
9. On GRO-B 1986, my father sustained an injury around the eye area whilst playing football and was taken to GRO-B He was advised by GRO-B GRO-B to spend the night, due to the fact he suffered from haemophilia. At the time, he was quite aware about blood being contaminated with HIV as he had heard about it in the news. He therefore made a point of telling anyone he

came into contact with at the hospital that under no circumstances was he to receive any blood products.

10. His friend [GRO-B] accompanied him to the hospital and heard him say this repeatedly. [GRO-B] has since passed away but his son, [GRO-B] has detailed his account of what happened, which has been exhibited at **WITN3225002**.

11. My mother took us to the hospital at around 10pm. My father's eye was closed and puffy, but other than that he seemed fine. When he came home from the hospital, he was furious. He said that when he was asleep around 2am, he woke up as he felt a prick in his arm. At first he assumed it was a drip used to rehydrate him, but then realised there was a blood machine whirling around at the bottom of his bed. By the time my father realised what was happening it was too late; he received one bottle of NHS blood and three bottles of Armour blood without his consent.

12. He was discharged the next day and around six weeks later became very ill. He could barely walk and spent the next six months flat on his back. He had an awful metallic taste in his mouth and didn't understand what was wrong with him, causing him great anxiety. His GP [GRO-B] came to the house as he was far too sick to attempt to visit the surgery. [GRO-B]
[GRO-B]

13. This was the first time my father was aware he could potentially have the virus, although at this stage it wasn't confirmed. He had all the symptoms and the six week incubation period also seemed relevant. [GRO-B] was advised by the hospital to test for Hepatitis.

14. A further document from [GRO-B] states 'Patient given Hepatitis' before 'Hepatitis' is crossed out and replaced with 'Factor 8'. This has been exhibited at **WITN3225004**.

15. Awaiting the results of the test was an awful time for my parents as not only did they not know if the virus had been contracted, but also if whether he had

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passed it to my mother. His diagnosis was eventually confirmed on 18th April 1986 by **GRO-B**

16. We also later obtained a letter from **GRO-B** which indeed confirmed my father had contracted Hepatitis C on this particular incident. The letter has been exhibited; **WITN3225005**.

17. Information about what my father had contracted was very limited and most of the information he had was through his own research. At this time they only knew the virus as Non A Non B Hepatitis, which he found out from his friend/GP; not whilst being treated in the hospital or immediately after getting home like it should have been. We were not warned of the risks of transmission to my mother, sister or myself, which was very irresponsible.

18. Information and support was so limited that my father helped to set up a support group for other victims funded by the Liver Trust.

19. My father was later tested for HIV; the test for which fortunately came back negative.

Section 3. Other Infections

20. My father received a letter telling him that he may have been exposed to vCJD but that they would not know if he had contracted the virus until his death. He therefore spent the rest of his days not knowing if he had the virus.

21. We had to send my father's brain to Edinburgh to be tested, but are still awaiting the results, along with his death certificate.

Section 4. Consent

22. My father consented to being tested for Hepatitis C and HIV after he was given the blood products, but he certainly did not give consent to receive the blood products.

23. Based upon previous experience, I have no doubt GRO-D Head Haematologist/Consultant of the Haemophilia Society knows how and why such contaminated blood products were used. I am happy to be interrogated further on why I believe GRO-D is the key to answers.

Section 5. Impact of the Infection

24. After contracting the virus my father was never the same again. He was yellow in colour and would just lay there ill. He was severely fatigued, nauseous and would constantly be vomiting. With his illness, he became short-tempered and depressed. He picked up infections all of the time and his legs were mottled either black, dark brown or red. The whites of his eyes were yellow and he said it felt like he had a terrible flu but even worse.

25. Before contracting the virus my father had been earning an excellent salary which sustained a comfortable family life. However he had the potential to earn an awful lot more and pension to go with it. Upon leaving school, he was involved in electrical engineering before he became a UK sales manager for a lighting company. When he became unwell he was limited to claiming statutory sick pay. My mother had to go out to work to help pay the bills and I remember having to buy them a lawnmower because my parents couldn't afford one. My sister had to take on my mother's role and do the household chores when she came home from school.

26. Everything happened at such an unfortunate time as my parents were in the process of buying a business, but had to hold off with the venture due to the circumstances.

27. As the years passed, I witnessed a number of symptoms associated with the virus. I used to feel so sorry for him and got extremely angry with the stigma that went with the virus. Everyone's ignorance towards Hepatitis C was very much the same as with HIV. There were people who were supposed to be close friends, who instead spread gossip. We therefore received a lot of

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comments from people in the community about his illness. We all put up with snide, horrible, comments about homosexuals and people having sex with monkeys. He worked part time, because he was unable to work full time and work colleagues put skull and crossbones on his mug so that no one would drink out of it which was very upsetting for him. It was probably the first time I ever saw him cry, which in turn became very distressing for me.

28. My father would go on the odd weekend away but no-one would want to share a room with him so he would get so upset about the comments that people made.

29. I recall being on a date and being asked if my father had Hepatitis C because he had heard rumours. After I confirmed the rumours were true, I never saw him again. I remained at home until I married in 1998.

30. My father struggled with his health and never knew when his liver would finally pack up. We were always just waiting for the call. As a mother, I felt the same for my father, as I do for my children; protective. It made me so upset and angry. Sometimes I would cry myself to sleep. I couldn't understand why such a good man was treated so disgracefully.

31. As time went on, my father's health became progressively worse. He wasn't fit enough to take the dog for a walk or go up stairs and was forced to move into a bungalow. He developed cirrhosis and liver cancer, which ultimately led to liver failure and death.

32. Physically, my father suffered from swelling of the legs and ankles, abdominal pain, an enlarged spleen, jaundice, severe cramps in his hands and legs, muscle wastage and pains and severe itching which he said felt like bugs crawling under his skin. He was so uncomfortable which meant he was unable to sleep, especially due to his internal organs being squashed by ascites.

33. The depression became quite severe when my daughter was born. He was unable to drink socially which left him feeling excluded. People thought he was a recovering alcoholic as he abstained from drinking.

34. He couldn't get life insurance and no dentist would treat him. They said it was too costly as they would have to disinfect all of the instruments. In the end he could only go to one NHS dental practice where he shared a waiting room with mentally handicapped patients. I once remember him saying he would rather lose his teeth than go through that again, which meant he died with wobbly teeth and ulcers in his mouth.
35. He also had a problem with arthritis within his knee which normally would have required a knee replacement. However, due to the infection he was told he wasn't able to have one. Proper pain relief wasn't an option because of the state of his liver, so he could only have paracetamol and not much of it at that.
36. My father had to go through weekly drainage of ascites, during which 9/10 litres of fluid would be extracted from his abdomen. He was absolutely exhausted and every trip became increasingly difficult. For one of these later visits, I drove my parents to the hospital and he was sick the entire journey, which was very upsetting.
37. The last procedure was three days before my father died. He had a permanent drain fitted inside his stomach. The large tube protruded through his stomach and was held in place by a stitch, coiled up and placed in a large dressing.
38. My father passed on GRO-B 2019. I kept a diary of the last few days of our lives, detailing his health and everything that he was going through. This diary has been exhibited at **WITN3225006**.
39. Even in death my father was not free from the virus. He was denied a proper burial as he was not allowed to be embalmed. We couldn't go and see him because he was zipped up and was covered with 'HIGH RISK' warning signs. He lay in the mortuary with drug users and the lowest in society.

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40. How would anyone feel if their loved one was in that position? His body isn't even intact as they had to remove his brain to be sent to Edinburgh to be examined for vCJD.
41. I cannot begin to express how my father's infection has affected us as a family. We had to keep our feelings from my father because it would upset him too much. My sister battled with clinical depression. She is no more than a 10 minute walk from my house and I have constantly looked after her as her ex-husband worked a lot and she needed that extra support. My family circumstances have meant, I have not been able to even contemplate working full time. Luckily I have a very understanding husband who works extremely hard, sometimes 7 days a week, so that I was always able to look after my family.
42. I couldn't go on to further education because I had to help bring money home. I ultimately ended up going back to college when I was in my mid-20's, but I was severely impacted by this late start to further education.
43. I kept my private life private. A lot of people I worked with couldn't understand that and always thought I had something to hide. I just wanted to stay close to my parents and my sister. I loved travelling but I felt guilty if I booked a trip away. Every winter if we suffered from the flu, my children and I could only see my father through the front window because we were frightened that he would catch something from us.
44. It was difficult no matter how hard we tried to keep it private. I worked part time close to where I lived and the company I worked for were awful. I had faces made behind my back and comments which were really nasty. I left when I became pregnant with my first child with no intention of returning. We were always fed up with people trying to pry into our private life.

Section 6. Treatment/care/support

45. My father was so desperate to clear the virus that he tried four different treatments, all with terrible side effects. He underwent treatment with Interferon, Ribavirin, Pegylated Interferon and Sofosbuvir with Ribavirin. The last course of treatment consisted of 13 tablets per day, which he thought was a lot for his liver to process, only for the treatment to be ineffective and receive a prognosis of 4-9 months to live.
46. My father's first course of treatment was on 4th March 1996 and was supposed to last for 3 months, but he had to end the treatment early as he just couldn't stand it.
47. My father's colonoscopies and gastroenterology procedures were carried out with 'dirty instruments' which were sent from Edinburgh. These were instruments that had been used on risky patients who could potentially be carrying the vCJD virus. He wasn't aware in the early days of this but he became aware after reading a letter from one of the hospital staff to his GP. He was treated like a contaminated being that no one wanted to perform medical examinations on. He said 'they've already given my Hepatitis C, it's likely they'll give me vCJD as well.' He was made to feel worthless and unwanted.
48. I went to my GP and asked if I could try counselling, which I did twice. I have managed to get by with alternative therapies and very supportive friends. I have never been approached for guidance help or counselling and have spent the last 30 years worrying about my family. I always want to be close by to ensure I am available to help them.

Section 7. Financial Assistance

49. My mother had to fight for Disability Living Allowance (DLA) for my father and to prove that he was ill. The application was initially refused, so they had to

appeal and sit in front of a panel of four people, which they hated and found traumatic and degrading.

50. My father was not made aware of any Skipton payments. It was by pure chance that he was speaking to his haematologist, Jason Mainwaring, that he found out about the Skipton Fund. He looked into them and found out he could have received the payments a lot earlier if he had been informed about them, but he didn't even know they existed. My father eventually started to receive monthly payments but by this stage he felt like he had been forgotten about.

51. My father was at the end of his life when he was sent a huge form to fill in by the DWP DLA to re-apply. He was so upset at this stage, knowing he only had a few weeks left to live yet he still had to beg for help. Fortunately, a member of the MacMillan team helped him to complete the form.

Section 8. Other Issues

52. My father wanted people to be held accountable for what happened and he wanted my mother to never have to worry financially.

53. This has completely devastated our family life. It has caused us unimaginable stress and anxiety and completely made us lose trust in humanity. My father was one of the loveliest people you could ever have met and he didn't deserve what was given to him.

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54. NOT RELEVANT

55. I would like to give oral evidence to the Inquiry.

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Statement of Truth

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

Signed..

GRO-B

Dated.....

24 / 8 / 19