

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3034001

Exhibits: 0

Dated: April 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. My date of birth is GRO-B 1959. I live at GRO-B with my husband of GRO-B years.
2. I am writing this statement in relation to my late father, GRO-B: F. He was born on GRO-B 1929. He died on GRO-B 1997, following an operation for a liver transplant after which he never regained consciousness. He required the transplant as a result of being infected with the Hepatitis B Virus (HBV) and later developing liver cancer. I was 38 years old at the time of my father's death.
3. This witness statement has been prepared without the benefit of access to my father's 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

4. I grew up in a little village in Yorkshire, with my mother and father. We had immediate family and friends/neighbours living very close by, with whom I spent much time with. My parents divorced in GRO-B when I was GRO-B years old and my father remarried in around GRO-B.

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5. I maintained a very close relationship with my father even after his divorce. There would be no set arrangement as to when I would see him, but as he only lived 5 miles away from my mother and I, he was still very much a part of my life. Due to my age and that particular period of time in my life, I did not consider my parents my biggest priority. In addition to this, I was training to become a GRO-B at college in Cumbria from 1978-1982.
6. My father was diagnosed with Rheumatoid Arthritis when I was about 10 or 11 years old. Soon after I was tested for the condition too, however the results from my blood test came back negative.
7. My father had always had a keen interest in horses and so became an avid GRO-B in his youth. This resulted in a lot of pain in his hands and feet, along with numerous broken bones. I believe he ended up having two knee replacements, an operation for excessive bone spurs growing from his foot and potentially an operation for his hands. He had to wear medical shoes that were specially made. He later became a GRO-B and then finally a GRO-B.
8. Growing up, I recall him having many operations and injections, at the GRO-B GRO-B Harrogate District Hospital and GRO-B near Leeds. Types of treatment in the 1960s included, gold injections and dipping his hands in melted wax.
9. He tended to maintain quite a "clean lifestyle." I remember he used to smoke a little but stopped when he was quite young. He never drank; alcohol was never really in the house, nor would he ever visit the pub.
10. Initially he was registered with BUPA as per the benefit package offered by his employer and so first started going via them for some of the injections for his arthritis. He also had various blood transfusions. I believe that one of these transfusions caused the infection.
11. I do not remember the exact dates of these operations but they were some time in the 1980's or 1990's and mostly undertaken at GRO-B. I am also unsure about the names of all the consultants and doctors he was seeing at the time. I have tried to gain access to my father's medical records from Addenbrooke's Hospital to find out why the transplant failed, but have had no luck. I am told they have been destroyed/are no longer available.

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12. I believe my father was diagnosed with Hepatitis B in the mid 1990s at the GRO-B
GRO-B Although I do not remember the exact date, I can clearly recall the conversation we had when he told me.

13. At that time I was working as a primary school teacher in GRO-B and got myself a HBV vaccination. My husband worked in the health service, within the maintenance department and was offered a HBV vaccination through work. There was a big issue with working in the wards and so closely to infected patients. Similarly, with my working as a teacher. It was all very new and no guidelines were in place.

14. My father's care was transferred from the Royal Free Hospital to St Mary's Hospital in London, (which I believe was upon instruction from his consultant.) I am unsure as to the exact reason why. I believe he was under the care of Dr Thomas and his assistant, Mary Crossley.

15. He was to be monitored on a regular basis, with regular check-ups and appointments with the doctors in London initially every six months, then three and then every ten weeks. He had several tumours/abrasions on his liver and it more a case of when they would turn cancerous, not if. Shortly after, the medical professionals found a tumour on his liver that progressively became cancerous.

16. My father was referred to Addenbrooke's Hospital for a liver transplant, following the discovery of the cancer.

17. We had one false alarm; we received a call from the hospital late one evening to say a liver was available. My husband and I left our home in GRO-B and drove through the night to Cambridge. We arrived and met my father and step-mother only to be told the liver was not suitable. This was before the days of mobile phones, so we turned back around and drove home. We travelled around 400 miles that day.

18. A week later, another transplant was scheduled so my step-mother, my husband and I checked into a B&B in the local area, whilst my father was prepped for the procedure. We were all with him at the hospital before he went into theatre. The trauma of having to say goodbye to my father as he was taken in was horrible. It was the last time I spoke to him. I told him I loved him and told the staff to take care of him. We then waited until the transplant was complete, almost 5 hours later.

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19. I was not in regular correspondence with the consultants, we just had to sit there and wait for him to get out whilst the procedure was taking place. The whole experience was horrible. When my father finally came out of theatre, he was kept in the intensive treatment unit for a week. As that week went by, my father's condition quickly deteriorated. He was not taken off the ventilator and never regained consciousness. My father's cause of death was pneumonia.
20. The decline in his health came as a major shock to us because the doctors had originally said that my father was the perfect candidate for a liver transplant. We were told that this was the only reason as to why he was eligible for surgery, as he was relatively old at the time. As the week progressed, it was evident the transplant had failed and he was put onto a ventilator. We then had to make the very difficult decision to take him off and let him rest peacefully.
21. I tried to find out what actually happened after the operation a few years ago, but the majority of the staff members no longer worked there. Additionally, there appeared to be issues with the records available. We were never given a proper reason as to why the procedure had failed. "Liver transplant" was the stated cause of death; however I do not have a copy of this.
22. I am not sure if my father was given any information regarding the risks associated with an operation of this severity. I am sure that I was not given any information of this nature. All I know is that the surgeon was a professor, so I can only assume that he was at the top of his field. I believe it may have been Professor Thomas.

Section 3. Other Infections

23. My father developed liver cancer as a result of his HBV infection. I am not aware of any other infections or medical complications arising as a result of his HBV status, apart from depression, itching and pain in his liver.

Section 4. Consent.

24. I do not believe my father consented to having his blood tested for medical or research purposes and do not know whether he was tested.

Section 5. Impact

25. Before my father was diagnosed with HBV, he used to be very chatty, outgoing and an all-round social individual. Once he was made aware of his infected status, he quickly became withdrawn and anxious and would spend the majority of his time in front of the television, watching the horse racing. He did not have much interest in doing anything else and was scared to go anywhere in case he received notification of an available liver for transplant, via the pager he was given by Addenbrooke's Hospital.
26. He made sure to carry a card to say he had been infected and on one occasion when he was asked about this and whether he had been with prostitutes, became incredibly upset because he hadn't.
27. He became obsessed with his health and his psychological state deteriorated quickly. He was always a very private person and so only immediate family would have known about his diagnosis. This included his 2 sisters and 1 brother, all of whom were older than him.
28. Physically, he was in terrible pain and had horrendous mood swings that really impacted his daily life. I believe he became quite depressed and anxious, (although he did not take medication for this.) All of this was coupled with the symptoms he was already experiencing from the Rheumatoid Arthritis.
29. His diagnosis was devastating on the family. The long term impact was horrible and I remember everybody being on tenterhooks all day, on the day of any appointment. No-one really had a good knowledge on the matter at the time, so people would just assume things about his condition. It was not a case of 'if' he died, it was 'when'.
30. During this time, I was trying to hold down a full time job as a primary school teacher but on the day of my father's check-ups, I would not be able to concentrate on work.
31. My father was working at the time of diagnosis; however the news was a contributory factor for his retirement at the age of 62, as issues with his mobility became apparent. My stepmother continued to work, but there would have been a great financial burden with the travel to and from London for each appointment and sometimes staying in a hotel. My father was only able to have a short retirement before his passing 3 years later, with much

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of this time taken up with hospital appointments. After a while, it seemed as if his life began to revolve around his check ups.

32. On the day of the final check up, my father went to St Mary's Hospital on his own. He rang to let us know that the check up was okay but I had a feeling that it was not. He then travelled all the way back to Yorkshire with the knowledge that he had been diagnosed with liver cancer. When he later called again, I was out and so my husband broke the news of my father's cancer. After this I felt as though I was living on a knife edge; it was draining and stressful.

33. On one particular occasion after this, my father came over for lunch, but he was sick and all he could do was lie in bed the entire time. At this point, I realised I was losing my dad and that his liver cancer was now a real threat to his life.

34. I believe he was in significant pain towards the end of his life, battling the effects of the infection, the cancer and the symptoms experienced from the Rheumatoid Arthritis. You would never know how he was going to be on a day-to-day basis.

35. Although not many people were aware of my father's Hepatitis B diagnosis, I know of one particular episode where he experienced stigma. The dentist that he had been going to for years just flat out refused to treat him. Eventually, the dentist agreed to provide treatment but only on the basis that my father would wait until the end of the day to be seen, so that the dentist did not have to re-sterilise his room and equipment again.

Section 6. Treatment/Care/Support

36. I was never offered any counselling or support as a result of my father's infection. There was much talk of counselling following his initial diagnosis and in reality, after we left the hospital, that was it.

37. He was satisfied and grateful for the treatment provided to him, although fearful of the MRI scans due to his claustrophobia. He was from a generation that would not question the medical profession. He would never complain and would trust that they were doing their best. He did not really have any complaints. My father was the model patient – he would do whatever he was told. My stepmother was appreciative as well.

Section 7. Financial Assistance

38. I am not aware of any financial assistance that my father may have received.

Section 8. Other Issues

39. Following my father's death, I was told by Addenbrooke's Hospital that they would send the death certificate to me. It never arrived, so my husband and I had to drive to Cambridge and register the death ourselves. Due to all the worry and trauma we were going through, we were involved in a minor collision on our way there.

40. My greatest sorrow is that my father missed out on so much in life.

41. My step-mother has been robbed of her husband and has been alone for 20 years.

42. He was robbed of retirement and I was robbed of him and his support when I was diagnosed with GRO-B on two occasions. I miss him.

Anonymity, disclosure and redaction

43. I would like to apply for anonymity. I understand that my statement will be published and disclosed as a part of the Inquiry.

44. I would consider giving oral evidence if required.

Statement of Truth

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

Signed... GRO-B

Dated... 29 June 2019