

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN7136001

Exhibits:

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 July 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1996, I currently reside in Scotland and details of my address are known to the Inquiry.
2. I intend to speak about my stepfather GRO-B: SF and his infection with Hepatitis C ("HCV"). In particular, the nature of his illness, how it affected him, the treatment he received and the impact his illness had on our family's lives together.
3. My dad passed away on GRO-B 2021 from liver cancer which had spread to his hip, back and neck.

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1. I am providing this statement with the support of my mum, GRO-B My dad has also given an account in a statement to the Inquiry, see GRO-B.
4. I am currently awaiting placement as an engineering officer GRO-B from September this year. I was accepted onto GRO-B training; however, due to my dad's passing, I postponed the start of my placement.
5. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me NOT RELEVANT
6. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

Section 2. How Affected

7. I grew up with SF and he was my dad. My mum and SF met in Thailand in 2003 and were married on GRO-B When they met, I was seven years old. At the time, my dad was living in South East Asia and running his own business. In 2007, my dad moved back to Edinburgh to set up his painting and decorating business.
8. My dad, in his account to the Inquiry, described the incident that led to him contracting HCV. In 1986, my dad was bitten by a police dog. The cut was very deep to the extent that you could see exposed bone. He was rushed to Western General Hospital, where he was given six pints of blood and plasma.
9. After my dad's return to the UK in 2007, he had to have a check-up to register with a new GP. The GP ran some tests the results of which

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confirmed that my dad had liver disease. He later found out he had been diagnosed with HCV, but the doctors did not explain what this meant to him and told him it was curable.

10. My dad did not want to worry my mum, so he did not inform her of his HCV diagnosis. According to my dad it was a busy time with planning the rest of the family's move to the UK so he did not want to inflict any additional stress on my mum.
11. Shortly after his diagnosis, my dad received treatment for HCV in the UK. Looking back, my mum says it was now evident when my dad was receiving treatment because he had stopped drinking for about six months. I believe the treatment consisted of Ribavirin tablets and weekly injections of Interferon. The treatment worked, and my dad was cured of HCV. However, it is our belief there should have been regular check, on at least a six monthly basis to ensure the virus did not return.
12. In 2020, my dad was complaining of pain in his side. He thought he may have twisted his hip, and he went to see his GP. The GP recommended physiotherapy, which did not work, and then prescribed medication which also failed to work.
13. Finally, they carried out blood tests and scans, the results of which confirmed that my dad had liver cancer which had spread to various sites in his body, including his hips, neck, and underneath his ribs.
14. The day my dad was diagnosed with cancer was when he finally confided in me that he had previously been diagnosed with HCV and had received treatment for this, but now he had been diagnosed with cancer linked to the HCV. He did not want my mum to know at the time.
15. We struggled to get further information about my dad's condition from doctors in the UK and sought doctors' opinions in Thailand and

Belgium. On each occasion, after looking at my dad's scans, the doctors asked if my dad had ever been diagnosed with HCV or Hepatitis B (HBV).

16. These doctors explained that my dad's liver cancer was directly linked to the HCV infection because the root of the cancer was located in the bile duct, which is at the core section of the liver. According to what we know now, for other types of liver cancer not related to HCV, the root of the cancer is usually identifiable from different sections of the liver.

Section 3. Other Infections

17. I do not believe my dad contracted any infection other than HCV due to receiving infected blood.

Section 4. Consent

18. I do not know if my dad was ever treated or tested for the purposes of research.
19. My dad consented to take part in a cancer trial ran by Dr Allan Christie however, I believe my dad was concerned about whether he had consented to some of the treatments he received as part of this trial.

Section 5. Impact

20. When my dad provided his statement to the Inquiry in 2020, he had just been diagnosed with cancer. Despite his cancer diagnosis, he remained fit and healthy and was optimistic about the treatment and his future.

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21. In November 2020, he began radiotherapy treatment under the care of Dr Allen Christie at the Edinburgh Royal Infirmary and Western General Hospital.
22. Dr Christie recommended that my dad began treatment as part of a trial of a drug which was unnamed at the time. He explained that the trial treatment protocol contained many elements which were quite expensive.
23. The treatment consisted of a course of various medications rotated into six cycles. After the third cycle, tests confirmed that the treatment was not working. Once it was concluded that the treatment was ineffective, Dr Christie abandoned my dad and stopped coming around to see him. As a family, we felt like my dad had been experimented upon.
24. My dad suffered from some adverse side effects while on the trial, experiencing a tingling sensation on his right side and feeling generally weak. It also had an adverse
25. Before my dad began the chemotherapy treatment under Dr Christie's trial, he was referred to an orthopaedic surgeon for the pain in his hips.
26. In a meeting with the orthopaedic surgeon where other medical professionals were present (i.e., other orthopaedic doctors and a cancer nurse), the orthopaedic surgery team believed that the cancerous tumour on my dad's hip could be removed before he began any chemotherapy treatment for the other tumours.
27. The doctors explained that they would need to seek the authority of Dr Christie. Ultimately, it was Dr Christie's decision that the cancer should not be removed and that the chemotherapy trial should go ahead before fixing my dad's hips. In addition, Dr Christie said the Chemotherapy (trail) could also help in reducing the tumour.

28. Looking back, it is our (my mum and my) view now that had the tumour in his hips been removed at an early stage, my dad would have had mobility, a better quality of life and could have still been with us today.
29. As time went on, the condition of his hips deteriorated, and my dad could no longer walk, move, sit or lie down. His inability to walk was mentally debilitating for him as he was an active sort of guy. He had always been both physically and mentally strong.
30. He could no longer do things he loved, like painting, decorating and going on regular walks.
31. In addition, my dad was advised that he could carry on eating and drinking normally, including alcohol while undergoing this chemotherapy trial.
32. Now our knowledge is such that we believe my dad should not have been allowed to consume alcohol, and that advice was incorrect.
33. My dad was reliant on the advice provided by the NHS. He trusted the advice, and as much as we as a family would argue against it, he had implicit faith in both the medical professionals and the NHS and would resist any persuasion otherwise. This led to numerous arguments between us and it was hard for us as a family.
34. My dad had been so happy to be part of the trial because he believed that he could be involved in saving other people's lives too.
35. It felt as though the doctors were aware of my dad's impending death and therefore did not care to provide proper advice about managing his condition.

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36. At one stage, we sought private treatment at the Rutherford cancer centre in Northumberland, for which we paid ourselves, as a family. There, my dad was provided with radiotherapy treatment on his hip. Here again the doctors at the Rutherford centre questioned why my dad had not already been treated with radiotherapy on his hip via the NHS, and we could not provide an answer as a family. What the answer was I had been asking for some time, and the doctors had fobbed me off.
37. My experience of communication with Dr Christie was that he constantly sought to avoid speaking to me. For example, shortly before my dad passed away, when he was critically ill, I asked to talk to Dr Christie and was told he was unavailable. However, as soon as I left the hospital to attend to my dogs briefly, he suddenly came around to see my dad.
38. By the time I returned to the hospital, Dr Christie was nowhere to be found again. I always felt like he sent out junior doctors and other colleagues in his team rather than communicating with me directly.
39. Dr Christie was regularly late for appointments with my dad. We sat around waiting for ages until someone else had to come around, and my dad would end up seeing another doctor instead.
40. I sought updates and permission for second opinions from other medical professionals, such as an oncologist, but I was left waiting for answers until my dad died.
41. When I questioned Dr Christie about the growth of my dad's tumours and why he was deteriorating so quickly, Dr Christie did not have the information and seemed to be measuring these from scans on the spot.

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42. In the last ten days of my dad's life, the doctors sent him back home. Dr Christie and his team advised that my dad should not be given food or drink, and we were only allowed to moisten his lips. Even this advice was questioned by our GP. The GP confirmed that since my dad could eat and swallow, why was it that he was not allowed to eat or drink? On the first day my dad returned from the hospital, he asked for food and cola to drink.
43. It seemed evident that the doctors believed my dad would die quickly. After my dad passed away, one of the nurses exclaimed that she was surprised my dad had lasted ten days after returning home.
44. My dad was admitted to Edinburgh Royal Hospital several times because he was in pain. Sometimes, the nurses would overdose him on painkillers because they thought it would help.
45. On one occasion, he was given five painkillers in one night, and he lost consciousness, even though it was already in his medical notes that one of the medications had been proven to be ineffective. On another occasion, they did not contact my mum before giving him a catheter. The information was only given to us after the event.
46. The process to allow my dad to come home to die was also a challenge. The hospital staff informed us that it was not within their experience for someone to choose to die at home and that the standard practice was to go into a hospice facility.
47. Before my dad was sent home, someone wrote down on my dad's medical notes that they had had a conversation with us (the family) and had agreed that my dad was not to be resuscitated. However, no one had spoken to us about this and the instruction was completely incorrect. In fact, we had been there in the same room and the doctor never once looked at us, let alone had a conversation with us.

48. While my dad was dying, I was struggling with a system that was preventing him from receiving proper treatment. I had to wait a long time for Dr Christie to provide a referral letter allowing my dad to receive private cancer treatment at the Rutherford cancer centre. The centre stated that they were surprised at the delay and difficulty they had in obtaining this.
49. I feel like the system was stacked against me and ultimately against my dad. He was only 61 years old when he died, and all of his health issues emanated from the contaminated blood which infected him with HCV.
50. Since losing my dad, I have struggled emotionally. My dad and I were very close, and he was my best friend. It has impacted so many areas of my life, and even my appointment to the GRO-B has had to be delayed because of the loss of my father.
51. I used to open up to my dad, and we talked about everything. I am close to my mum, but it is not in the same way. Not having my dad around anymore I feel lost and unsure about my path in life.
52. My dad was supportive of my every move, and I miss him so much. I thought he would be alive to see me graduate GRO-B. He had so much hope for the future. He even planned to be travelling around the world with hopes of visiting me while I was carrying out my GRO-B training in various countries.
53. Losing my dad has affected my mum massively. We are a small family and have always been close-knit, just the three of us. My dad was a happy and positive person who always joked around the house.
54. My mum can't sleep properly anymore since my dad's passing. Six years ago, she was diagnosed with rheumatoid arthritis, and recently it

has been changed to fibromyalgia and now she won't have the support of her husband while she goes through ill health.

Section 6. Treatment/Care/Support

55. We were offered counselling support after my dad passed away, but I do not wish to make use of this for personal reasons.

Section 7. Financial Assistance

56. My dad received the stage one payment of £20,000 from the Scottish Infected Blood Support Scheme (SIBS).

57. After providing his statement to the Inquiry, my dad contacted the SIBSS to inform them that he had been diagnosed with liver cancer and received a further lump sum payment from the SIBSS.

58. Before his death, my dad left us with instructions on how to contact the SIBSS. After he died, we contacted the SIBSS and they covered the funeral costs.

59. My mum now receives a monthly payment from the SIBSS.

60. Since the death of my father, my stepsister has sought to challenge my father's will under Scottish law because she is my dad's biological daughter. Before his death, she had absolutely nothing to do with our family.

Section 8. Other Issues

61. Many people believe in the NHS, however, our experience has made us lose faith in it. A lot of the actions of the medical professionals made me question their effectiveness, knowledge and skill. My dad trusted

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the doctors and the nurses completely, but they did not look after him properly.

62. Doctors and medical professionals in the NHS need to be more empathetic when dealing with families of ill patients. It seems as though they do not listen and do not communicate with other parts of their services, for example between hospice care nurses and hospital nurses.

63. As I have said above, I feel like the system was stacked against me and ultimately against my dad. He was only 61 years old when he died and I believe he could have lived for much longer. All his health issues emanated from the contaminated blood that infected him with HCV.

Statement of Truth

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

Signed

GRO-B

Dated

28th / Sept / 2022