

# ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN5147001

Exhibits: **WITN5147002 - 004**

Dated: 20 January 2022

## INFECTED BLOOD INQUIRY

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WRITTEN STATEMENT OF **GRO-B**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 January 2022.

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

### Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** 1980 and I live at an address in Nottinghamshire that is known to the Inquiry.
2. I am married with three children, the youngest is less than a year old. I work as a senior manager in a local government department. I have been on maternity leave and am due to return to work in a few weeks.
3. I am the only child of **GRO-B: M** who tragically passed away on **GRO-B** 2011, as a result of her infection with hepatitis C ("HCV").

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4. I intend to speak about my mother's infection with, and subsequent death as a result of, HCV. In particular, the impact this had on her in the short time between her diagnosis with HCV and her passing and the impact that this all had and which continues to this day on me and my family.

### **Section 2. How Affected**

5. Mum was born on GRO-B 1958. She had a congenital condition, hip dysplasia i.e. a dislocated hip. As a result of this, she had surgery in 1959 and a further surgical procedure in 1960 to correct the previous procedure. I can remember seeing baby photos of Mum in a plaster cast up to her waist.
6. My maternal Aunt recalls that Mum spent months in hospital after both procedures, due to the seriousness of both operations. She remembers Mum crying when she was twice discharged from hospital. It was all she knew and thought it was 'home'.
7. Though Mum was too young to recall any of this to me in later years, she did tell me that my grandparents had informed her that the hip procedures had lasted hours and that she'd had blood transfusions.
8. My Mum and natural father separated before I was born and I was brought up by my Mum alone until I was 12 years old when she began a long term relationship with my stepdad, which lasted about 18 years before they then separated.
9. In December 2010 my Mum rekindled a relationship with her childhood sweetheart. She was in the process of selling the house that she had shared with my step Dad. Mum had never been happier at this point and was seemingly fit and healthy. She was living with her father, my grandfather, next door to me and my family. He had previously been living on his own but had developed dementia. This meant that Mum could look after him.

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10. In March 2011, Mum started to become unwell. She felt constantly fatigued and was experiencing pains in her stomach. She also started to see blood in her faeces. This persisted for a number of weeks until she collapsed.
11. We rushed her to Queen's Medical Centre ("QMC") where she remained for a month. During this time, I gave birth to my daughter, the second of my three children, in GRO-B 2011.
12. Between April and July 2011, Mum went to QMC regularly for tests and exploratory examinations to determine the cause of her illness. In the early stages of this, the hospital identified that she had cirrhosis of the liver.
13. Mum didn't drive so I would take her to the hospital for her appointments and wait outside in the car. One day around July or August 2011, after an appointment with her consultant Dr James, she returned to the car and told me that she had been diagnosed with HCV.
14. Mum told me that the consultant had explained to her that she had contracted HCV from blood transfusions received during her operations in 1959 and 1960. Aside from this, Mum didn't tell me anything else about the consultation.
15. During my training I was taught about blood-borne viruses and routes of transmission, hence I knew what HCV was. I also knew about cirrhosis of the liver, but believed it to be primarily associated with alcoholics.
16. After Mum's diagnosis with HCV, she was admitted to hospital on a regular basis. During one visit the nurses called us in because they thought she was going to die. The veins leading into Mum's liver were bleeding and the doctors feared that they were going to burst open. They said that she needed 'banding', which I understood to mean they put little bands around the veins which stops them bursting and assists them to continue working.



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17. Mum regularly had episodes of coughing up blood and on one occasion vomited blood everywhere, it was like a scene out of a horror film.
18. Mum's health deteriorated rapidly from September 2011 onwards. She was referred to Addenbrooke's Hospital, Cambridge, in October 2011 where she was assessed for a liver transplant. This gave us all a lot of hope that Mum would recover.
19. During this period, Mum underwent a range of tests to determine whether she was suitable for a liver transplant. She was in Addenbrooke's Hospital for two weeks, during which time she had a liver biopsy.
20. The consultant at Addenbrooke's phoned me, I remember it being GRO-B and he told me that Mum had liver cancer and would therefore be unable to receive a liver transplant. We went to Cambridge the next day and were with Mum when she was informed that she had liver cancer and that it was terminal. I was told that she had months. I asked the doctors if she could come home for a period. We were told that she could be allowed home for palliative care. However, she never made it home, the assessment of her having months left turned out to have been optimistic.
21. Mum was taken back to QMC on GRO-B 2011. The following day, my aunties, Mum's sisters, went to visit her. The doctors said to them that if the internal bleeding started again that there was nothing more they could do except make her as comfortable as possible.
22. I went to see Mum that night, on GRO-B I remember it well as it was GRO-B and we were watching the fireworks from the window of her room. Mum began bleeding internally and consequently the doctors administered strong medication that led her into an unconscious state and she was made comfortable.

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23. Mum was put on the 'Liverpool Care Pathway', a palliative care process that in general terms was the subject of some controversy, though I did not know that at the time. Nothing was explained to me about this, or the fact that it had been heavily criticised. Despite this, it wouldn't have made any difference to Mum as she was unconscious and at end of her life stage.

24. Mum remained in a state of unconsciousness for three days when on GRO-B GRO-B I got a call from my aunt at the hospital, saying that she thought I should go, implying that mum was close to the end. I left for the hospital immediately. Just as I arrived in her room on the GRO-B 2011, she took her last breath and passed away. It was as if she had waited for me to arrive before departing.

25. It was just six days between Mum being diagnosed with cancer and her untimely death. When I went to see the registrar to collect Mum's death certificate, I saw that the primary cause of her death had been recorded as 'cirrhosis of the liver'.

26. I was unhappy about this and refused to accept the certificate as it was. I said that I didn't want people to think that my Mum died because was an alcoholic. This was simply not true. I also didn't want people to think that Mum was an intravenous drug user because HCV was listed as a cause of death.

27. I sat in the registrar's office for over an hour waiting for her to change the death certificate. She duly did so and afterwards said that she had never experienced anyone asking for a death certificate to be changed before.

28. Mum's cause of death was recorded on the Death Certificate as I(a) Hepatocellular carcinoma (b) Liver Disease and Cirrhosis (c) Hepatitis C Infection. I exhibit Mum's death certificate as exhibit **WITN5147002**.

### Section 3. Other Infections

29. Mum did not have any other infections.

#### **Section 4. Consent**

30. Mum was just a baby when she underwent the two operations in 1959 and 1960 respectively. Mum had two further operations on her hip in 1991 and 2003, which she would have consented to, I am sure. I have been asked by the investigator if I knew what month in 1991. I am afraid that I do not but I understand that this may be significant in relation to when blood began being screened.

31. I believe that Mum consented to all testing and treatment for her HCV infection and liver cancer.

#### **Section 5. Impact**

32. Up until her diagnosis, Mum was genuinely the happiest she had ever been. She had got back together in a serious relationship with her childhood sweetheart. The sale of her house meant that she would get £50,000, which was a huge amount of money for Mum. She treated herself to some new clothes but it was very soon that everything began to deteriorate as she became increasingly unwell.

33. Despite her HCV diagnosis, Mum was positive and hopeful that she would get better. We all were. We had pinned our hopes on the liver transplant, so to hear that she had terminal liver cancer was absolutely devastating for everyone.

34. I was my Mum's only child and we were very close. I was her whole world. She adored me and I adored her. She loved being a mother and a grandmother. She loved her two grandchildren and it deeply saddens me that she was unable to see them grow-up.



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35. Mum had worked in a local's pub for 10 years prior to her illness. She was well-liked and well-known by everyone in the local area. By the summer of 2011 she was forced to stop working due to her fatigue. Instead, she used to just lie in bed. She hated not being able to work and missed the social aspect of her job.
36. Mum also missed the birth of my daughter in GRO-B 2011. This upset her as she wanted to be with me and help me through it but she couldn't be there. She struggled enormously with being unable to interact fully with her grandchildren.
37. The birth of my third child, in 2021, brought back memories of Mum's final months. Mum was around at the time of my first two being born and her not being there enhanced my feelings of loss. It was also ten years since she had passed away, for me a milestone that reignited my grieving.
38. The biggest impact of Mum's death for me is the fact that she has missed all the important and wonderful life events that a mother should witness. I was the first person in my family to go to university but Mum died before I graduated. She didn't see me get married. She wasn't around for the birth of my third baby. Mum would have loved to have been with me for all these massive life events, as much as I desperately wanted for her to be there.
39. I remember when Mum was dying, she used to apologise for silly things such as shouting at me when I was 15 years old. We had an incredibly strong relationship with one another. In her last weeks, Mum said to me that I must keep on going after she was gone.
40. It was this that kept me going after her death. Mum's passing had a hugely significant effect on my mental health. I sought out a bereavement counsellor from the charity 'Cruse' and had counselling every week for over a year. I was diagnosed with anxiety and depression

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and I was prescribed antidepressants for 18 months after Mum's death. I was also unable to return to work for a while.

41. My mental health is still affected now. Knowing that I was coming here today to speak with the Inquiry's investigator has been playing on my mind.
42. Just this morning, my stepdad's best friend phoned me. I immediately thought that this was to inform me that my stepdad had died. It was not but this is typical of the anxiety attacks and is indicative of how my mind works ever since my Mum died. I was not like this before. I still suffer periods of anxiety more than ten years after she passed away.
43. Another example is my stepdad being unwell over Christmas. I automatically thought he would die. I now have an ingrained fear of losing those closest to me.
44. I never had a sense of mortality and I had never experienced grief and loss prior to Mum's death. I changed forever on the day she died and I can't go back to the person I was before. This impacts on all my relationships, including my children who I know I am overprotective of. My fear of losing someone else is constant.
45. I have also developed a fear of flying, where there was none before. I am scared that I will die and I have to have a few drinks before I can even contemplate getting on a plane. Its irrational I know but very real to me.
46. I was fearful that I may also be HCV positive, even though I had been tested twice during my pregnancy and found to be negative. Despite this I went back to my GP more recently and wanted to have another test done.
47. I still find my Mum's death incredibly distressing, over a decade afterwards. It took me eight years after her death for me to properly celebrate my birthday. Our birthdays were two days apart so it was



always called 'our' birthday. My anxiety used to increase in the weeks building up to my birthday.

48. The distress had subsided but it comes back in waves. On the 10<sup>th</sup> anniversary of her death, it felt like a big milestone and I found it very difficult in the weeks leading up to it. I struggled to sleep and I was anxious. After it passed, the wave of anxiety began to subside and things settled down. I am better able to manage my wellbeing now but I can only bring Mum's death back up on my own terms and deal with it in my own way and to my own manageable extent.

49. It wasn't in my life plan that Mum would miss all the big events in mine and my families' lives. My world blew apart completely and she was taken from us far too soon. I had to let it go that someone was responsible for her death, even though no one has ever acknowledged that.

#### **Section 6. Treatment/Care/Support**

50. I do not believe that Mum faced any difficulties in obtaining treatment in consequence of her infection with HCV. Though the timescales subsequent to her diagnosis, meant that treatment to clear the HCV was never even talked about.

51. I was never offered counselling or psychological support by the NHS. Neither was Mum, as far as I am aware.

52. I took it upon myself to speak to a specialist bereavement counselling charity who provided weekly counselling for over a year and for free. I don't think I would've been able to finish university or to carry on functioning without this support. These appointments helped me enormously.

#### **Section 7. Financial Assistance**

53. I think the consultant, probably Dr James, told my Mum about the Skipton Fund. I think she then told me about it. It certainly wasn't a priority at the time as we were focussed on getting Mum better.
54. I think Mum and I discussed applying to the Skipton Fund when she was being assessed at Addenbrooke's Hospital. I researched it on the internet and I believe Dr James completed the form in support of Mum's application.
55. I submitted the application as a trustee of my late mother, around January 2012. She had said that she wanted me to do this. It was far more about recognition by the authorities of what they had done to her, than it was to do with money.
56. The application was rejected in a letter from Nicholas Fish dated 28 January 2012 (exhibit **WITN5147003**) on the basis that I had no medical records proving that Mum received a blood transfusion during her operations.
57. This letter led me to go off and try and gather more information. I discovered that the specialist orthopaedic hospital where Mum was treated as a baby was closed and I was informed that the records had been destroyed. I applied for Mum's GP records and found 1 letter from 1960 written by the orthopaedic surgeon which confirmed that Mum had a surgical procedure but did not confirm that she received a blood transfusion.
58. I recall writing to the Hep C Trust who advised me to contact the QMC for Mum's records but I was subsequently informed that these had been destroyed also.
59. I enclose a letter sent by Dr James to Professor Wallace of the orthopaedic department at QMC dated 21 February 2012 (exhibit **WITN5147004**). Professor Wallace treated Mum after her operation in

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- 1991, and accordingly Dr James asked for some assistance in locating any documentary evidence that she received a blood transfusion, although Professor Wallace was unable to locate any records.
60. Within this letter, Dr James wrote that Mum 'had no other risk factors for acquiring hepatitis C other than a blood transfusion received during her surgery, aged 2, in 1960 for a left CDH.'
61. I did all I could but I was unable to find any record proving that Mum received a blood transfusion. I appealed the decision of the Skipton Fund, enclosing the letter from Mum's GP records and a personal statement.
62. This appeal was rejected. The panel's view was that there was no evidence that Mum received a blood transfusion and the clinical facts of the case meant that she would not have required a transfusion. They said that they would reconsider this if I went away and found evidence that the operations Mum received in 1959 and 1960 would have necessitated a blood transfusion.
63. I found this completely ridiculous. How could I possibly go out and find that out? I was asked to do the impossible. The records had all been destroyed and how could I possibly prove this? Who did they expect me to speak to?
64. I weighed it up and decided that I didn't want to obsess over this for the rest of my life. I accepted that pursuing this would just prolong my healing process. I found this a very difficult decision to make but I had to leave it. I felt that I had failed in the last thing I could do for my Mum.
65. On reflection, I question why the Skipton Fund bothered asking the opinion of Dr James, a senior hepatologist, as to how my Mum contracted HCV, when they apparently didn't take this into account.
66. I made that application to the Skipton Fund in good faith in the hope that the people responding to it were experienced and cognisant of the issues



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at hand. I later learnt that this wasn't the case. I read and heard Nicholas Fish's evidence to the Inquiry and I was appalled to learn how little training and experience he had of these issues.

67. Nicholas Fish did not have the requisite level of knowledge necessary to make those decisions. To think that he was making life-changing and hugely impactful decisions about peoples' lives is shocking. I was extremely upset and angered when listening to his evidence.

### **Section 8. Other Issues**

68. The medical professionals who cared for Mum when she was a baby presumably treated her to the best of their abilities and to try and make her life better. They would have had no knowledge that the transfusions she received were contaminated and would ultimately lead to her death.

69. I hope that the outcome of the Inquiry is to result in organisational change to better help those infected and affected directly by these issues.

70. I feel that the Inquiry needs to look at the human impact and I hope it doesn't lose sight of this when looking at government and organisational policy.

### **Statement of Truth**

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

Signed

GRO-B

Dated 20-01-22