

ANONYMOUS

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Witness Name: GRO-B

Statement No: WITN5548001

Exhibits: WITN5548002-6

Dated: 14th JULY 2022

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 16 November 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1953 and my address is known to the Inquiry. I live in Suffolk with my husband, GRO-B We have 2 grown-up children together. I am retired but I have previously worked as a carer and also as a caterer.
2. I intend to speak about my mother GRO-B who was born on GRO-B 1931 and her infection with Hepatitis C (HCV). In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.
3. I wish to be an anonymous witness due to some family disputes that have arisen in relation to mum's care.

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4. I am not legally represented and I am happy for the Inquiry Team to support me in providing this witness statement. These are ongoing.

Section 2. How Affected

5. On [GRO-B] 1968, mum, dad and my 2 younger siblings were involved in a [GRO-B] accident [GRO-B]
[GRO-B]
[GRO-B] mum [GRO-B]
[GRO-B] suffered severe injuries including a broken jaw and numerous broken bones. (See Exhibit WITN5548002)

6. I remember dad saying to me that my little sister [GRO-B]
[GRO-B] He even covered her up with a blanket as he thought she was dead. Mum [GRO-B]
[GRO-B]
They were taken to [GRO-B] Hospital following the accident, where mum was immediately given a blood transfusion due to the significant blood loss she had suffered.

7. [GRO-B]
[GRO-B]
Unfortunately, [GRO-B] mum and dad didn't get any compensation for the accident.

8. I was around 15 years old at the time and had been out with friends that day. They had come back to our farmhouse and we were having hot chocolate when there was a knock at the door and it was my Uncle [GRO-B] He said something like, 'you are partying and enjoying yourself when your mum and dad are fighting for their lives', I had no idea what was going on at this point as I had not heard about the accident. He asked my friends to leave and he explained to me

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what had happened. He told me to get my pyjamas as I would be staying with my aunty [GRO-B] and my other brother [GRO-B] was already there.

9. The next day, I was taken to the hospital waiting room to see if I could visit my family. I heard lots of screaming and crying which was upsetting. One of the doctors took me to see my sister [GRO-B] and she was unconscious. She was just [GRO-B] months old at the time. I asked if I could see my parents and I was told I could not and the best thing would be to go home. I stayed with my Aunty [GRO-B] for a number of days before going to stay with my Aunty [GRO-B] so I could continue going to school. I stayed with her for a long time.
10. I was attending [GRO-B] at this time and I recall that they would let me walk over to the hospital so I could sit and talk to [GRO-B] who was still unconscious, as they thought this might help her recovery. I recall just sitting talking to this 'doll' for a long time – she looked so still and lifeless, then one day she woke up. I'm not sure how long she was unconscious for in total.
11. During this time, mum was having a lot of reconstructive surgery done to her jaw. Even after significant amounts of surgery she continued to have no feeling in her jaw and had to touch around her face when she was eating in later years. She was treated by a consultant called Dr [GRO-B]
12. Eventually, after a while, dad and [GRO-B] came home from the hospital, although I don't remember spending much time with them. My cousin who was a bit older than me came to live with us during this time.
13. I'm not sure exactly how long mum was in hospital for in total following the accident, but it was a significant amount of time. Her health never fully recovered and a few years after the accident she started to suffer from various ailments.
14. [GRO-B] and I married in [GRO-B] and I remember mum having various issues with her health around this time. She went to see her GP at [GRO-B] in [GRO-B] on numerous occasions before moving to [GRO-B] when

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my parents' moved addresses. They didn't know what was wrong with her and she was always in and out of hospital for tests. I remember dad saying, 'back to the hospital again and we still don't know what's wrong'.

15. Over the years, I knew mum suffered from mood swings, aches and pains and tiredness, almost to the point of exhaustion. She also had trouble sleeping and joint problems, particularly her wrists, ankles and knees but I'm not 100% sure what else was wrong with her. After many years of years of going back and forth to the doctors, her GP concluded that there was something wrong with her kidney, but this turned out to be an incorrect diagnosis.
16. In around 1996, mum was finally diagnosed with HCV at Addenbrookes Hospital (**See Exhibit WITN4458003**). I'm not sure how they decided to test her for HCV or whether they discussed this with her before testing her. Dad was still alive at this point and took mum to most of her appointments.
17. We knew nothing about HCV and dad was not given much information about it or how to manage her condition. The only thing dad was told was not to have contact with mum's blood or bodily fluid, and I think he passed this information onto us.
18. I think it was clear to the doctors treating mum that her HCV was linked to the multiple blood transfusions she had received following the accident in 1968. Mum had no other risk factors for HCV. She never used drugs of any kind and had no tattoos or piercings. She had never undergone major operations where a transfusion was required and was happily married.

Section 3. Other Infections

19. I am not aware if mum was ever tested for HIV or any other infections. As far as I am aware, she was only infected with HCV as a result of the blood transfusions she received.

Section 4. Consent

20. As mum was in such a serious accident, the treatment she received would have been emergency treatment and they would not have been able to ask for her consent prior to giving her blood transfusions. At the time it would have been a matter of life and death.
21. I am not aware if mum was asked to consent to being given an HCV test as dad attended these appointments with her, but I doubt she understood what was going on. I believe they were only told about the HCV test after the results had been received.

Section 5. Impact

22. When we found out that mum had HCV, none of us knew much about it and dad was dealing with it all despite his own deteriorating health. I don't think my parents really knew what the implications of this diagnosis were. They were country folk that worked in farming in the middle of nowhere and had no medical knowledge.
23. I don't think mum ever asked the doctor any questions about HCV and I'm not sure if dad did either, as he was becoming quite poorly by this stage. We were all quite naive about it and even I had no knowledge of it until I started doing my own research. We knew so little about HCV that we didn't even know whether mum's other health problems were linked to the HCV.
24. I don't think dad was ever tested for HCV and there was never a suggestion that the rest of the family get tested either. Much later on when looking after mum I asked my GP Dr [GRO-B] if we should be tested and he said that it would only be necessary if we had symptoms, but I had no idea what initial symptoms for HCV even were! He reiterated that I should not touch mum's bodily fluids and if I was careful, I should be alright.

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25. Not long after mum's diagnosis, dad found out that he had leukaemia but he never told us what exactly was wrong with him. I only found out that he had leukaemia when I took him to an oncology appointment at Addenbrookes Hospital. Despite being extremely unwell, dad looked after mum instead of himself. He was always doing things for her and I am sure that the stress and worry about her and her condition was responsible for speeding up his demise.
26. Dad started to prepare for when he would no longer be around to help mum, as he knew he was dying. He said that they were finding it difficult to manage as they lived in a very remote part of GRO-B in Suffolk on their own. When the bungalow next door to me became available, he asked how I felt about them moving in next door to me which I said was fine. I think he wanted to make sure there was someone close by to take care of mum when he was gone. He sold their house for a ridiculously low price to get it sorted quickly and they moved in next door.
27. When we helped mum and dad move into their new place around December time, dad was actually in hospital. As he became more and more poorly, dad asked me to look after mum when he was gone and I promised that of course I would. As the eldest daughter, I took on this responsibility. A year later, he passed away in 2000 at just 69 years old.
28. Dad's death was extremely upsetting for the whole family and mum was so upset that he was no longer there to take care of her. She suffered from severe depression due to dad's death and possibly due to her ongoing health problems. She found it very difficult to cope.
29. A specialist came to the bungalow at some stage to help mum with her depression. They thought she might also have dementia but this was ruled out. Mum had been quite a big lady before but she ended up losing a lot of weight over the next few years in part due to her depression but also likely, a side effect of her HCV. She was prescribed strong antidepressants and was on these for most of her life after this point - I'm not sure if she ever came off them.

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Mum also had very little money after dad passed away which compounded her depression, but I saw her through it. It was a very difficult and emotional time.

30. Mum was in no fit state to drive after Dad died so I would take her to her appointments. She had regular blood tests but nothing was mentioned about treatment for her HCV. She had aches and pains, some rashes, arthritis, problems with her knees and excessive tiredness yet difficulty in sleeping. She would also bruise very easily and bleed significantly if she had a cut, but these symptoms were never linked to her HCV.
31. Mum had some appointments with Dr [GRO-D] in relation to her HCV and liver at the Hepatology Department at Addenbrookes, and I think she had a biopsy when first diagnosed and another biopsy in 2000. However, her care for it seemed to fizzle out. I think there may have been the occasional ultrasound and it felt like there was nothing they could do about the HCV and all of a sudden there were no more appointments arranged for her in relation to this and the focus was on her other health problems. There was never any explanation that this was course to be taken – it just happened.
32. Although I worked as a carer and a cook [GRO-B] in the community for some years after dad died, it became increasingly difficult to look after mum's needs while working and taking care of my own family. As [GRO-B] was self-employed, he would occasionally have to change his work schedule if I had to do something for mum, but we tried our best to work around it. Our children were grown up by then and understanding of the situation and thankfully [GRO-B] was very supportive.
33. I loved my job in care work and was due to go on a course relating to drug administration for patients so I could move up in the field. However, I was too emotionally invested in mum's care by this point and mentally I could not cope with balancing everything, so I decided to pack it in. It was hard to give up a career I adored, but I had promised dad that I would look after mum.

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34. In around 2007, I started to do some GRO-B from home which was on an ad hoc basis. I became quite busy and eventually had to get someone to help me, but in the last 4 years of mum's life I had to give it up as her care took up so much of my time. I could not commit to enough jobs to earn enough for the business to make financial sense. Although I went back to it for a short time after mum died, I eventually gave it up and retired.
35. Being forced to give up work caused us to suffer quite a significant financial loss but I can't put a figure on it. GRO-B had to work longer hours to keep us all and to pay our mortgage.
36. I was doing everything for mum by this point including cleaning for her, making all her meals, helping her with her personal care and taking her to various doctor's appointments. My daughter and niece would go in to do her hair and pedicures, but it was just me doing the other things, despite mum having 3 other children. I would keep gloves in the house for anyone who visited and I told people that they could go and kiss mum and do whatever, but not to have contact with her blood.
37. One day about 3 years or so before mum died, bruises started appearing over her body and she suffered a rectal bleed. I took her to GRO-B and we sat there for hours and hours. When they eventually saw her, they wouldn't let me come in with her. I had been there about 4 hours when I saw mum again and she said they hadn't even examined her. They assumed she had piles and that it was not significant.
38. Sometime after this incident, mum rang me up to say that something wasn't right and she couldn't move her arm. Alarm bells started ringing in my head and I thought mum might be having a stroke. I rushed over to her and called an ambulance, and went through all the symptoms over the phone with the paramedic. An ambulance came from either Peterborough or Kings Lynn and the paramedics could not find a pulse in her arm.

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39. Mum was rushed to **GRO-B** Hospital initially and was then taken to the intensive care unit at Addenbrookes Hospital. They put rings around her bruises to monitor how they spread. I don't remember what they diagnosed her with in the end, but it wasn't a stroke and she recovered. They said she had suffered from some under skin bleeding.
40. During this time in hospital, mum was kept in an isolation room but I think they were just trying to get to the bottom of why she was having the bruising. She was also connected to a lot of special equipment, but was eventually moved to a general ward.
41. Not long after this in 2011, mum had a knee replacement surgery and ended up in a high dependency ward in a coma. I sat with her every day during this time. I was asked by the doctors whether mum should be resuscitated if it became necessary, and I said no at the time, which caused a disagreement within my family. I had been looking after mum and had seen how she had deteriorated over the years, whereas my siblings had not. She had no quality of life and was very unwell.
42. She was in a coma for quite some time, and I think she was in hospital for a long while. I thought mum was going to die but she eventually came around from the coma and she was moved to a general ward, which we were all surprised about. A palliative care nurse came to visit mum at some stage after she had woken up. She held mum's hand and said, "Mrs **GRO-B** there is nothing more we can do for you". She explained to mum that she could either go into a hospice, stay in Addenbrookes Hospital or go home.
43. Mum wanted to go home but I told the nurse I just couldn't cope on my own. I was totally drained by this stage and did not know how I could take care of her. They said they would try and organise a live-in carer, which she had for the last 7 months of her life. Mum had foreign carers and they were absolutely brilliant. However, mum was very fussy about her food so I continued to do all her cooking and I was still providing her personal care during this time. Mum also

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required some injections in her last couple of months, and my daughter would come and do them for her as I struggled with this.

44. I recall one incident that happened during this period where mum hurt herself while in the shower, and blood was spurting everywhere. I bandaged her up but I had to get the doctor to come out due to the severity of the bleed. When the doctor arrived, he said I had done a good job in stemming the flow of blood, but I told him to go look at the shower, which was absolutely covered in blood. The carer and I had to wear full protective gear when cleaning it up, due to the risks associated with handling mum's blood.

45. As I mentioned above, after dad died mum was unable to cope with day-to-day life and I managed all of her affairs including her finances. I had power of attorney for mum and I managed all of her bills and withdrew her pension for her, as this was not something she could do on her own. She also made me sole executor of her will.

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GRO-B

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GRO-B

48. As I was so upset by what was happening, I didn't go to mum's house for a few days and she was just with her carer. She then called me to say that she had no shopping in and I told her to call her son to sort it out – I was still very angry

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However, I eventually went over there as I was worried about her, and told her to give me the list of things she needed and I would get them for her.

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GRO-B

50. The night before mum passed away, I had been with her. Her favourite carer GRO-B was taking care of her and as I left that evening, I said I would be back the next morning to help. The next morning, I had my coffee and went to mum's and GRO-B was making her breakfast in the kitchen. I greeted her good morning and went to see mum in her bedroom.

51. When I walked into mum's room, I could immediately see that something was not right with her. She looked at me, took one huge breath and passed away then and there on GRO-B 2014. I was there when she died, but had not been there long enough. There was no chance to say a proper goodbye.

52. I shouted down for GRO-B who took mum's pulse and told me she was gone. We stood by mum's bed and GRO-B started to pray and sing one of her South African songs. I just said thank God that her suffering was now over; she had suffered so badly. It was not an easy thing to go through and now I had to tell my children. They loved their grandmother to bits and really felt her loss.

53. I called mum's GP and said I think mum has passed away. They said since there is nothing that they can do, someone would come to the house after surgery. I wasn't happy with this and asked for someone to come as soon as possible. A doctor came 3 hours later and confirmed she was gone. I asked what she had died of and the doctor said HCV, although this had not really been monitored much in the years leading up to her death.

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54. Mum's death certificate listed her cause of death as Chronic Viral Hepatitis C and Hepatocellular Carcinoma. (See Exhibit WITN5548004). No-one had ever mentioned that mum had cancer, and this was quite a shock to me. I was stunned by it in fact. Nothing had been mentioned about treating this either, and I know this because I attended all mum's doctor's appointments with her.

55. I later learned that this had been discovered during a biopsy in December 2009, and had actually been included on the Skipton Form written out and endorsed by Dr [GRO-D] from Addenbrookes. (See Exhibit WITN5548005). I don't understand why this was never discussed with us and why mum was never offered any treatment in relation to this. Surely in five years something could have been done?

56. Mum was cremated and her ashes were placed with my dad. There was no mention from medical staff that this should not happen due to her HCV, and it was down to her wishes. My brother did not let me see mum's will even though I was the executor, but I just couldn't fight it, her death was still too raw at the time. He hated that he was not in that role, but this was mum's choice.

57. [GRO-B]
[GRO-B] I have 3 siblings, and I have had nothing to do with them or their children since mum's death [GRO-B] The last time I saw my sister was 2 weeks after mum died. I am only close to my own husband, children and grandchildren.

58. I don't believe our family would have ended up so fragmented if mum did not require the care she needed due to the HCV. [GRO-B]
[GRO-B] This has been particularly difficult given how much I sacrificed in my own life for mum, ending up on antidepressants due to the impact it had on me. I feel angry with mum too because I feel like she was

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playing the family against each other on occasions and didn't do enough to stand up for me nor ask the others to help out with her needs.

59. I was on anti-depressants while looking after mum and then stopped taking them but I have been on anti-depressants for the last 2 years

GRO-B

GRO-B

Dr GRO-B my

GP,

GRO-B

GRO-B

He has asked me if I have thought of taking my own life as I do get very down. I told him that I don't want to be here but even so, this isn't something I would do.

60. Thankfully I have not faced any stigma in relation to mum's HCV and neither did mum. I have only told close friends about mum's condition and never really broadcast it. They knew I was sensible and taking precautions when coming into contact with mum's blood.

61. My children lost their gran whom they loved dearly but they were old enough to understand and at least had some time with her. I feel for my husband who had to work long hours to compensate for the loss of my income and to keep the family financially stable. There must also have been an impact on our personal relationship due to the stress I was under but he never complained and was never anything other than supportive. There are still problems with the ongoing situation with my extended family and he is caught up in these as well. These are something unlikely to have arisen without the impact of my mother's illness.

Section 6. Treatment/Care/Support

62. As far as I am aware, HCV treatment was never discussed or offered to mum. I attended all her appointments with her after my father died in 2000, and this was never mentioned. She had very few appointments specifically related to HCV over the years.

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63. We were also not told that she had developed hepatocellular carcinoma, and I only found this out when I saw her death certificate. I do not why they did not consider treating her for HCV, bearing in mind she was diagnosed in 1996 or for the carcinoma.

Section 7. Financial Assistance

64. I can't remember exactly how I found out about the Skipton Fund. I think it was Dr [GRO-D] at Addenbrookes Hospital that mentioned it and I did my own research into the Fund. Mum was struggling financially after dad's death and this is why I wanted to get her the financial support she deserved. She was worried about how she was going to manage, although I always told her we would help.

65. I applied to the Skipton Fund on mum's behalf for the first time in September 2008, but her application was initially rejected due to a lack of supportive evidence in relation to her transfusion. (See Exhibit WITN5548006) I had contacted [GRO-B] in order to gain access to mum's medical records, but initially they said no records could be located.

66. In October 2008, [GRO-B] wrote to me again to say that they had in fact found some of mum's records which had been saved on microfiche. This was after I had continued to call them to push them to look for these records.

67. These records related to her [GRO-B] accident in [GRO-B] 1968 and confirmed her blood transfusion. (See Exhibit WITN5548007) Due to the error in not locating these records previously, they waived the £50 for the records they usually charge.

68. When I provided the Skipton Fund with these records, they approved mum's claim and she received her first payment of £20,000 in November 2009. She was very surprised to receive this and I remember her saying, "what am I going to do with £20,000?". She bought herself a new Craftmatic adjustable bed and some other furniture to make herself more comfortable.

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69. I have a feeling the Skipton Fund contacted me about applying for the second stage payment. She received an additional £25,000 payment for this in around January 2010. In May 2013, Nick Fish wrote to us to say that this was being increased and mum was now entitled to an additional stage 2 payment of £25,000. This meant that she received £50,000 in total as part of second stage payments.
70. I didn't know about mum having cancer at the time, but it turns out that mum was entitled to this additional payment due to the HCV causing her hepatocellular carcinoma. Dr GRO-D had included this information on her Skipton Fund form for the additional payment.
71. The money from the Skipton Fund helped mum enormously and gave her peace of mind. I continued to pursue the Fund following the initial rejection, as I knew mum deserved some support given all she had been through.
72. When mum died, the Caxton Fund provided a small amount of money towards her funeral.
73. I have tried to register with EIBBS but I have had some conflicting information from them. On the 19th November last year, I received an email from them saying that they would add my name to a list and they would create a record for my mum once they receive historic files from Russell-Cooke. However, having corresponded with them further, I later received a reply saying that they did not understand what my query was and they asked why my mum's files should be sent to them. On the 16th December, I received an email saying they had received the papers from Russell-Cooke regarding my mum and discussed a funeral grant which had already been claimed. The only other thing they said was that "Estates and family members of deceased beneficiaries can apply for the counselling discretionary payment." They said if I required an application form, I was to respond. I did not take this any further at the time. Overall, I have found the process very frustrating but I am considering following up with them.

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Section 8. Other Issues

74. Mum's infection with HCV through infected blood has not dented my faith in the NHS. I cannot fault my own GP Dr GRO-B Maybe we should have been given more information, but they were brilliant generally. The fact we were never informed about the cancer was never explained. I would like to know why but it's a long time ago now and will not bring mum back. However, something like that should never happen to any family.
75. Mum shouldn't have been given the blood in the first place but I don't think they knew it was infected. She was at the wrong place at the wrong time and it is as simple as that. I'm not going to knock them in relation to this.
76. I would like to add that it still plays on my mind as to whether I could have contracted HCV from my mum as I did everything for her. Even as recently as when I last spoke to the Inquiry team, I tried to contact my doctor regarding this and was unable to because of Covid restrictions at the time and it is something I will consider going forward.

Statement of Truth

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

Signed X GRO-B

Dated X 14th July 2022