

ANONYMOUS

Anonymous

Witness Name: GRO-B

Statement No: WITN5765001

Exhibits: WITN5765002

Dated: 30 December 2021

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 04 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 1951. I reside GRO-B Somerset, GRO-B I married my late-husband GRO-B:H in 2018; we were waiting for the civil partnership to be lawful between heterosexual couples. We have two sons together. I am currently retired, having formerly been employed as a GRO-B GRO-B in a variety of subjects, and as GRO-B

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2. I intend to speak about my late-husband [H] infection with Hepatitis C ("HCV"). Genotype 1a. There is some uncertainty as to exactly when [H] contracted the virus. We know it was from a transfusion but as to the exact date we were not clear.
3. In a letter dated 17th July 2019, From Dr Alexandra Hodsman (Consultant in Renal Medicine) North Bristol NHS Trust under the heading: **Diagnosis**, 1. *It reads. Established kidney failure in 1991 (Cause Unknown) 2. Iatrogenic Hepatitis C due to NHS administered blood transfusion under Fiona Gordon at the BRI. 3. 1992 first cadaveric renal transplant (lasted a week).* So looking at this now it would appear that [H] had a blood transfusion prior to his kidney transplant.
4. There is also another letter, dated 01-05-13 from Dr Saurabh Jain, SpR in Haematology to Dr [GRO-B] which states, Hepatitis C from blood transfusions in 1990. As you will note, there are several discrepancies re the date of the HCV infection.
5. In particular, I wish to discuss the nature of how [H] learnt about his infection, how his illness had affected him and our family thereafter, and the financial assistance we have received. [H] s date of birth is [GRO-B] [GRO-B] He worked as a landscape maintenance gardener and as a musician, before his death on [GRO-B] 2019. [H] was 70 years old when he died.
6. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I wish to be anonymous due to family reasons.
7. 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.
8. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life

events. However, these timeframes should be accepted as 'near to' rather than precise dates.

9. I was referred to the Infected Blood Inquiry ("IBI") from the Hepatitis C Trust, when I contacted them following a discovery of their newsletter on [H]'s email in 2020.

10. I have constructed this statement without access to [H]'s full medical records. That said, I am awaiting receipt of them from the medical practice. I understand the importance of identifying the exact date [H] had his first kidney transplant, hopefully the records will confirm that. There is confirmation in letter relating to a home visit in 15 October 2018 that [H] contracted HCV via a blood transfusion in 1991 resulting in sclerosis of the liver.

Section 2. How Affected

11. [H] and I grew up in [GRO-B] Somerset, and we were friends as teenagers.

[GRO-B]

[GRO-B]

[H] was a Landscape Gardener and I was teacher as well as a mother.

12. In 1989, [H] started to experience leg cramps and he felt very poorly. He decided to seek medical assistance from his local doctor at the [GRO-B] [GRO-B]. As a result of undergoing a number of tests, he was diagnosed with having developed severe kidney failure. [H] was then referred immediately to the Southmead Hospital ("Southmead"), Southmead Road, Bristol, BS10 5NB.

13. From 1989 until 1992 [H] was placed on dialysis therapy at Southmead.

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14. In 1992, [H] had undergone a procedure at the Southmead, whereby he had a kidney transplant. As I said earlier, hopefully [H]'s medical records will confirm the exact date of the transplant and the exact treatment he received.
15. I do not believe that [H] was provided with any information or advice beforehand, surrounding the risks of being exposed to a blood borne infection associated with any blood transfusion.
16. Following [H]'s kidney transplant, we were told that his procedure had been unsuccessful. He was placed back onto regular treatment with dialysis thereafter.
17. Around the mid-1990's, [H] attended a dialysis session at Southmead as normal. When he returned home, he had told me something along the lines of *"I have something to tell you. I got Hepatitis C from a blood transfusion."* In response, I asked him what he meant by this, to which he stated that we have to be very careful from now on around his blood and any bodily fluids as his Hepatitis C is very infectious.
18. It is my belief that the information [H] was provided with by the medical profession when he was diagnosed was not adequate to have allowed us to understand and manage his infection.
19. The only information [H] was provided, was surrounding the risks of others being infected as a result of his HCV. We were provided with warning signs that his HCV was very transmissible so we had to be very careful with blood and bodily fluids. We were not provided with any leaflets or what I would describe as life advice surrounding HCV as an infection. [H] was a very quiet man so maybe he should have asked more questions, but it was not up to him to ask.
20. At the time of [H]'s diagnosis, our two sons were very young, so we had to tell them to be careful when around their daddy's blood, without scaring them. They were aged 5 and 2 at the time.

21. [H] was on regular dialysis treatment during this period, so there was a lot of blood around. We would say to the boys, if they see blood, do not touch it. It was almost as if we had to tell them that dad was very infective, without saying the words. [H] had his own towel, and when the boys would go to touch it, I recall telling them *"No, that is daddy's towel."*
22. Retrospectively, speaking to my two sons, they have said that this period was normal to them, they did not know anything different.
23. Recently, when I contacted the Hepatitis C Trust, I was told a lot more information surrounding what was known about HCV at the time of [H]'s diagnosis. I wish more had been known about living with HCV at that time.
24. I do believe that the information surrounding [H]'s HCV infection should have been provided at an earlier point in time, which was when he was diagnosed. This would have allowed [H] and I to have a better chance at a normal marital relationship as we were both so scared his HCV could be passed on very easily. This impacted heavily on our marriage, we lived as one and couldn't share the intimacy we once had.
25. It is [H]'s impression; having been told by the medical profession during his HCV diagnosis, that the cause of his HCV was a blood transfusion he had received at Southmead around 1991.
26. I do not believe that there are other possible causes of [H]'s HCV. He was not ever a heavy drinker, he was not an intravenous drug user, and he did not have any tattoos or piercings.
27. Despite [H]'s HCV in or around 1999, [H] was called to undergo a second kidney transplant at Southmead, after another match had been made with a kidney donor. Following receipt of this news, we took [H] to Southmead immediately, where he was taken down to surgery to undergo his kidney transplant. [H]'s second kidney transplant was a success and he was discharged home to recover shortly after.

28. Following [H]'s successful transplant, it was an amazing feeling as normality had finally returned. We were able to go on holidays and spend time together as a family, where life was relatively well.
29. However, over ten years later, in 2010, we were told that [H]'s kidney transplant had failed, as the kidney had stopped working. Thereafter he started to develop other health problems, for one, his heart was enlarged, so he was taken to the Royal United Hospital ("Bath RUH"), Combe Park, Bath, Avon, BA1 3NG.
30. As soon as [H] was admitted to Bath RUH, he was placed into a coma in the Intensive Care Unit ("ICU"). After a short period of time, we asked the medical profession about [H]'s condition, to which we were told that he may not make it and they would only know once they tried to raise his consciousness. We were told to go away for an hour and come back. Only then, will they know the condition of [H]'s health.
31. Walking around the [GRO-B] for one hour felt like a life time. It was particularly difficult as this was where [H] and I had [GRO-B] [GRO-B]. Following one hour, we went back to Bath RUH to find out the fate of [H]'s health. Thankfully, we were told that [H] was okay, and that he had come out of his coma successfully.
32. Again after a short period of time [H] was transferred to Southmead, whereby he had to be placed back on dialysis treatment. [H] remained at Southmead for a period of around three weeks, before he was discharged home to recover.
33. In 2018, [H] found himself very breathless and we went to our local GP. He referred [H] to Yeovil, as they were the first to be able to treat him.
34. In hindsight with [H]'s health background this was not the best location for him which retrospectively was recognised by one of the consultants, [H] should have been referred to Bristol.

35. In any case [H] then underwent a number of tests. When the results of such testing had returned, he was told something along the lines of *"the results are really bad, have you had any treatment?"* In response, [H] had said that he had been having treatment at Southmead for his heart.
36. As it transpires, Southmead had not been testing [H] for around a period of one year, as they must have left him off the list. The medical profession at Southmead must have missed something, so he was not having treatment for one year.
37. Thereafter, a doctor at Yeovil got in touch with a doctor at Southmead, and [H] was asked to attend Southmead to undergo a number of tests and to discuss treatment for his heart.
38. When [H] and I attended Southmead for a face-to-face consultation with one of the doctors, we discussed [H] possibly undergoing a Tavi Procedure, whereby a valve would be fitted into the heart to treat aortic stenosis.
39. Within a short period of time, [H] received a letter at home from Southmead. The letter stated that he was unable to undergo the Tavi Procedure, as it was the doctor's belief that as his overall health was so poor, he would not survive the operation.
40. In response, [H] rang the doctor at Southmead and stated a question along the lines of *"so you are leaving me to die, are you?"* This was so out of character for [H] as he would not normally bother people or get angry, but this was such an important procedure.
41. We were then referred to the local GP re a second opinion; the GP told us that there was unlikely to be a better result. At that point he was referred for palliative care. The doctor then discussed the DNR process and we agreed for that to be put in place. There was obviously very little that could be done and it was a matter of time.

42. On [GRO-B] 2019, [H] attended an appointment for a dialysis session at the renal unit at [GRO-B]. When I went to pick him up, the nurse had stated that he would be out in a minute. Within what appeared to be a matter of minutes, they had said that there was a problem with [H] and that they were going to ring an ambulance. The nurse told me to go home and pack a hospital bag for [H] and then go straight to the hospital.

43. One of my son's and I went home, packed a bag for [H] and went straight to Bath RUH where we believed that the ambulance had taken him. However, when we arrived, the medical staff had told us that he was not at that hospital. No one knew where he had been taken, when suddenly, a member of the ambulance crew had told us that they had taken him to the [GRO-B]
[GRO-B]

44. When we reached the [GRO-B] it was so late in the night that the building was all locked up. We had to speak to a member of staff so that they could let my son and I into the hospital. When we saw [H] we knew that he was not very well as he was in and out of consciousness. One of the Doctors took us aside and said something along the lines of "he doesn't have long" I decided to drive back home to get my other son so that he could be there when [H] died. During the drive home, it was thunder and lightning. I remember it distinctly as it felt like such appropriate weather at the time.

45. Around 06:00am on [GRO-B] 2019, [H] passed away surrounded by his loved ones.

46. Within the Death Certificate of [H] dated [GRO-B] 2019, certified by M.Mehisen MB, (exhibited below, at WITN5765002), [H] cause of death is outlined as follows:

- 1(a) Cardiogenic Shock
- (b) Severe Aortic Stenosis
- (c) Severe Left Ventricular Failure Impairment (sic)

II End stage renal disease

47. I do not know why [H]'s HCV or sclerosis of the liver is not shown on the death certificate.

48. Prior to [H]'s death I had spoken about my wish not to have a funeral and that's exactly what we did with [H]. He had a Pure Cremation, as he and I did not want the fuss. I was also far too upset to have to go through that. As a family we still want to host a get together for all our friends to celebrate his life, however, as with most things at the moment Covid has put a pause on that.

Section 3. Other Infections.

49. As far as I am aware, other than HCV, I do not believe that [H] was infected with any other blood borne infection as a result of receiving a contaminated blood transfusion in or around 1991.

50. I am unaware as to whether [H] was tested for the presence of any other infection other than HCV in the past. If he had, then I was not made aware of this fact.

Section 4. Consent

51. I do not believe that [H] had been tested or treated without his prior consent having been obtained or without his knowledge, [GRO-B]
[GRO-B]

52. When [H] had received the blood transfusion around 1991 at Southmead, this would have been administered in an emergency situation, and I believe that this would have been provided where it was required. I also believe that the medical profession did what was necessary in the circumstances, for the benefit of [H]'s health. In any case, [H] would have consented to having been provided with this treatment.

53. It is mine and [H]'s belief that he was diagnosed with HCV as a result of testing of his blood which had taken place following the failure of his kidney transplant and having undergone dialysis treatment again. I do not know whether [H] was aware that these blood tests had been taken, but if he had, then it is believed that he would have provided consent.

54. Neither myself or my two sons have been advised to obtain a blood test for the presence of HCV, following [H]'s diagnosis.

Section 5. Impact.

Mental/Physical Impact

55. For the first forty years of [H]'s life, he was relatively healthy.

56. Prior to [H]'s diagnosis with HCV around the mid 1990's, there was no indication that he had been given contaminated blood, which had caused him to contract HCV. Even now looking back, it is difficult to distinguish between the symptoms of the issues with his kidneys and the HCV, as his kidney issues may have masked any HCV symptoms.

57. Between [H]'s first kidney transplant in 1992, and his second kidney transplant in 1999, [H] experienced a number of vascular issues, where he had to have a stent put in his groin as a result. [H] also had to undergo an operation on his throat as he had a build-up of calcium.

58. In 2010 [H] developed a melanoma in his chest. This was treated with radiation therapy at the Bath RUH.

59. In 2010, when [H]'s second kidney transplant failed, he experienced heart problems, his heart was enlarged as it was having to work really hard due to his other health issues.

60. In 2011, [H] attended his local doctors on several occasions to seek medical assistance surrounding an issue with his foot which was black in colour, painful, and had started to smell. [H] was then referred to a specialist foot doctor at Southmead, and after examining his foot; he had to have a partial left foot amputation of the infected toes. It is my belief that this was attributable to the medical profession not attending to his vascular problems in a timely or correct manner.
61. Thereafter, [H] had to undergo a second procedure, whereby they virtually amputated the whole of the top of his left foot. This made it difficult for him to be able to walk.
62. In 2011, [H] was diagnosed with Parkinson's disease, for which he received medication. This was a horrible disease as it eats away at the body gradually, to the point that he eventually became less mobile. [H] was a keen keyboard player, to which he played in a local band with his friends. Due to his Parkinson's, there became a point where he was unable to play his keyboard anymore.
63. In 2018, [H] also underwent a carpal tunnel procedure as he had lost some of the use in his left hand.
64. Also in 2018, [H] was referred to the Royal United Hospital Bath, which was [GRO-B] When we attended our first face to face consultation with one of the Consultants, (Dr Mark Farrant) we immediately noticed that he was a lot more forthcoming.
65. He explained a lot of things to us, and that [H] would need to undergo a number of tests, which may have included a Fibroscan. When the results of his testing had returned, he was told that he had developed severe cirrhosis of the liver. This had previously not been mentioned at Southmead. It was refreshing to be seen by a consultant who was more open and forthcoming with [H] s diagnosis.

66. We then had another meeting with Dr Farrant Consultant Gastroenterologist on 19 March 2019. In a letter from Dr Mark Farrant dated the following day to [H]s GP (Dr [GRO-B]), I note he writes: Severe fibrosis/cirrhosis (Fibroscan 14.8 in January 2016) Also, previous chronic hepatitis C infection virus cleared in July 2016 at the BRI.

67. I also note that Dr Farrant writes: *I think it would be inappropriate to subject him to any more ultrasound scans. Were we to find something I am not sure whether we would be able to do anything with the information.* [H] and [GRO-B] are in agreement with this.

68. [H] was always so ill. He had so much wrong with him. The renal issues took priority over anything else.

69. I do not believe that [H]s HCV diagnosis had an effect on his mental state of health. He was a very stoic man who was always so strong. He was quiet, friendly and reserved, who did not always make a big impression on others. Those who knew him really liked him as he was one of the nicest men you could meet. He was not a very social person, but he was a family man. However, from the point of his HCV diagnosis, it felt that he was always preoccupied in his mind, he was no longer free-wheeling.

Treatment

70. As far as I am aware, [H] underwent treatment to eradicate his HCV at the BRI. I recall him taking a course of treatment in tablet form, which may have been a twelve-week course. I recall being told that the treatment was very expensive. Documentation I have recovered shows that [H] was prescribed with Veikirax and Exviera plus Ribavirin.

71. [H] continued to have regular health check-ups. When he finished the course of HCV treatment [H] was informed that he had cleared the virus. This was excellent news and he was very relieved. It also meant he would be

able to have other health treatments which had been potentially paused as a result of his HCV infection.

72. The other change to his life was his dialysis. When he carried the HCV he had to undergo the dialysis in a room on his own. As soon as he cleared the virus he was allowed back in the communal room with everyone else, he was very happy about that.

Impact

73. I believe that [H]'s HCV has impacted on my two sons. When I have spoken to them recently, they have told me that looking back, they had been quite traumatised by that period. At school, they were aware of things that other children were not; such as the dangers if a child cut themselves, to be careful. They had become very hyper sensitive surrounding dangers.
74. [H]'s HCV diagnosis affected our marital relationship. We did not have sexual relations following his diagnosis, as he was scared that he would pass his HCV onto me. Our relationship was strong, but I believe that if someone had taken the time to talk to us about the percentage chances of passing on his HCV, then it would have made a difference. No one told us that it was rare to pass on HCV through sexual relations.
75. Looking back, [H]'s HCV impacted on the family unit. If it was not for my boys, my future would look really bleak. Following [H]'s death, I feel that I have been sliced in half, or lost half of myself. We knew each other as teenagers, so we depended on each other for a large part of our lives. He fought so hard with all of his treatments. I have a little shrine to [H] at home. I cannot bear the idea that I will never see him again.
76. I do not believe that either [H] or I experienced the stigma attached to HCV, as we did not tell others about his HCV status. I do not believe that we told our two sons about their father's HCV as they were of a young age at the time. Keeping this information to ourselves it makes you feel like a pariah, that

you have this large secret that you cannot tell others about it as it would alarm them.

77. Financially, before the Skipton Fund came into it, I worked full-time as a teacher. [H] would work when he was well enough. We have always been careful with money. We have managed okay. Financially, yes if he was working, we would have been better off.

Section 6. Treatment/Care/Support

78. I do not believe that [H] was ever refused treatment, care and support as a result of his HCV status. He has always been very grateful for the help and support he was provided when he was treated under the National Health Service ("NHS"). When I would be critical about the medical profession for one reason or another, he would always say that there is good and bad in everything in life.

79. I would say that the only time that [H] faced a difficulty or obstacle in the treatment and care he has received, was in 2018, when he was told by one of the doctors at Southmead that he was unable to undergo a Tavi procedure on his heart as it was believed that he was too weak to survive the surgery. Due to [H]'s kind and quiet nature, he would not normally make a comment, however, this was one time that he came back at the medical profession.

80. Neither [H] my two sons, or I have been offered any counselling or psychological support as a result of [H]'s HCV diagnosis. [H] would not have asked for support from the medical profession, as I hope he would have thought he would have received support at home.

81. However, in either January or February 2019, I was referred to the [GRO-B] [GRO-B] in [GRO-B], who have been very supportive. After [H]'s death, I was offered bereavement counselling at [GRO-B]

but as I was not in the right head space at the time, I did not take them up on their offer.

Section 7. Financial Assistance

82. In 2004, [H] was told that the Skipton Fund were providing financial assistance for persons who had been either infected or affected with HCV, by contaminated blood or blood product. I believe he then completed the application form himself, and sent them to the Skipton Fund.

83. On 6 January 2005, [H] was awarded with an ex-gratia stage one payment of £20,000 from the Skipton Fund. (Skipton ref no [GRO-B] refs)

84. Around July 2019, the money provided by the EIBSS went up in value. The revised payment as of July 2019 was increased to £1538.17.

85. Around 2020, I was going through [H]'s emails to see if there was anything to address, when I came across a Hepatitis C Trust newsletter. I decided to contact the Hepatitis C Trust, and it was here that I was told about the English Infected Blood Support Scheme ("EIBSS"), and that I may be entitled to some type of allowance or financial assistance.

86. Recently, I contacted the EIBSS to discuss [H]'s death, when I was told that as [H] had passed away longer than six months prior, I did not qualify for a lump sum payment. They did say that I might qualify for financial assistance if my income was not over £28,000 per annum, and an allowance of £200 a month.

87. More recently, I was contacted by the EIBSS, whereby I was told that I was entitled to more money, which would be backdated. I have no idea about the amount concerned.

Section 8. Other Issues

88. I would like the IBI to establish the truth surrounding the Contaminated Blood Scandal, so that this can be a lesson for the future. I do not want other people to be put in the same position as [H] and I. We were aware that the NHS was being squeezed financially, and that it was not the NHS that are at fault, but the greater powers that be. He appreciated the NHS and all that they did for him with regards to the other medical issues he experienced in the past.

89. The reason I am providing the IBI with a witness statement, is so that I can give him a voice. Before his death in 2019, he was always keen on something being sorted out, and for his story to be known about. As his death is still quite raw, this has been an emotional and difficult process to go through, but I am doing this for [H] It has also been a very cathartic process.

Statement of Truth

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

Signed GRO-B

Dated 30th December 2021

Table of Exhibits:

Date	Notes/ Description	Exhibit number
[GRO-B] 2019	Death Certificate of [H]	WITN5765002