

# ANONYMOUS

Witness Name: GRO-B

Statement No: W6905001

Exhibits: None

Dated: 18 JAN '22

## 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 17 September 2021.

GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1974. I live in the USA with my wife GRO-B and our three children. I am out here as a GRO-B for the Royal Navy. I am a GRO-B and an GRO-B I've spent much of my career under the sea and away from my family. I am originally from GRO-B and my parents still reside there.

2. I intend to speak about my mother, GRO-B: M GRO-B who was infected with Hepatitis C ("HCV") through a blood transfusion. In particular, I intend to speak about the nature of her illness, how the illness affected

## ANONYMOUS

her, the treatment she received and the impact that it had on our family and our lives together.

3. My mother supplied a witness statement to the Inquiry in 2019. It is important for me to provide an update to the Inquiry on my mother's current situation and on her behalf. During the period in which she was interviewed, her situation was stable, but this had since changed drastically. I believe that her current situation is significantly related to her HCV diagnosis, and therefore should be shared with the Inquiry.
4. Please note that I may not remember all of the relevant dates, as some time has since passed, and because of my work as a submariner, I have been away from my family a lot.
5. The Inquiry Investigator has explained the anonymity process to me. I am seeking anonymity and I wish for identifying factors to be redacted from my statement. I can confirm that I have chosen not to have legal representation and I am happy for the Inquiry's Investigation Team to assist me.
6. I can also confirm that the Inquiry Investigator has explained to me the 'Right to Reply' procedure, and 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 was born on GRO-B 1974 in GRO-B and I was extremely premature. Sadly, during childbirth, my mother was particularly ill and due to the loss of blood, she required a blood transfusion. My mum provides more detail on this incident within her own statement.

## ANONYMOUS

8. Following the birth, my mum recovered and her health from there was good. However, as I have been told, her mental health changed from that point onwards. She became a different character, according to my father, but nothing you would put it down to specifically. While I was growing up, she always had the odd mental health concern but we thought nothing of it at that point.
9. In around 2008 or 2009, out of the blue, my mum received a call from her GP and was invited in for a blood test. They told her that they had specifically traced her because she had a blood transfusion back in 1974.
10. She went in for the blood test. Shortly after, they wrote to her saying, "we've got the results back but we want to take another test, just to be sure." The need for a second blood test was striking to her.
11. She went in for the second blood test, and was then later informed over the phone that the tests had returned and she had tested positive for HCV. They told her that it was from a blood transfusion that she had around the time I was born, and they knew there had been contaminated blood used.
12. She was told quite casually. There was no warning really and it came as a massive surprise to her. As far as she was aware it had been a routine blood test.
13. She was well informed about the risks and what it meant for her. The internet is also a great thing as well. She had the same view as me really which was that nobody knew about contaminated blood products during that time.

### **Section 3. Other Infections**

14. I am not aware of my mum being tested for any other infections.



**Section 4. Consent**

15. I do not believe my mother was in a position or physically able to consent to the blood transfusion at the time. I think my dad would have done so on her behalf.
16. My mum's medical records state that she had a transfusion, but there is no other detail in there or no barcode of the blood products used. That does seem quite strange to me.
17. I do not believe the risks of a transfusion were explained but that back then, no one was aware of the risks, and at that moment, I can imagine the benefit of giving her a transfusion far outweighed any risks.
18. My understanding is that the doctors who treated her had a choice, and that they made the best choice available at that time. Either to not save my mother, or to carry out a blood transfusion, which they did not know was contaminated at that time. That treatment clearly saved her life, and therefore protected my upbringing as well, up until the point of hepatitis C diagnosis.
19. Later on, she consented to the blood test but I don't think she was aware she was being tested for hepatitis C. I believe she was not well informed at this point.

**Section 5. Impact**

20. When my mother was informed that she was hepatitis C positive, it was quite a blow to her.
21. My dad also had to get tested for HCV. This was really distressing for him but thankfully it returned back negative.

## ANONYMOUS

22. The diagnosis has had a huge impact on my mum. There has been a taboo in some parts of the family and it hasn't been spoken about. I believe the rest of the family didn't quite understand the diagnosis and what it meant. There was always a question, especially when her grandchildren were young, as to whether my mother should touch the grandchildren and so she didn't see them for some time as a result of this.
23. Due to the HCV, my brother said, "I don't think you should look after your grandchildren." I didn't really twig it at the time, but I should have challenged it. The risk there is so minimal and this goes hand in hand with the stigma attached to HCV.
24. They went from being so welcoming, to not allowing her near their kids. It was really difficult to challenge my brother on this. That must have been a real blow to my parents. But one that will never be revisited or corrected. It all must have been massively upsetting for my mum. It also led to her doubting herself and she even questioned whether you can catch Hepatitis C from inadvertently sharing personal items such as a toothbrush.
25. There was never an open conversation about HCV. Hindsight is a wonderful thing, but it's the thing that would have made the biggest difference, by speaking openly about it. I'm sure there are other families living in isolation on this too.
26. She was briefed about the more physical symptoms of HCV, which I understand some people have, but she didn't have any. She was expecting to have something like kidney failure but she hasn't suffered any of these kinds of problems.
27. Nobody ever spoke to her about the mental health aspect, which has been the more prominent problem for my mum, and we have realised that correlation recently. It was something she was never prepared for or that she has been able to understand. Also, part of the problem is the taboo around mental health as well.



28. In around 2007 or 2008, my mother received treatment for about eighteen months, and she now is negative for HCV. She was treated with interferon which had quite brutal side-effects on her. I think she administered daily injections. She suffered from hair loss and everything that goes on with that. It was successful but was brutal and this prolonged the course of treatment. The prolonging of the treatment could've had an impact on her mental health as well. I was away a lot with work during this time, and so I missed a lot of this, but my mum would always put on a brave face around me.
29. She recovered from the HCV but she was increasingly anxious over the years. Her grandchildren noticed some things related to her mental health during that time. Sometimes our kids would say Nanny's doing this or that, but she was still pretty stable.
30. My mum was not aware of the mental health effects and following the HCV treatment, I think my mother would have seen it as 'done and dusted'. She would have thought, "I'm now all clear - the treatment was a bit rough, that was a bad phase in my life, but it's over now."
31. During the Covid-19 pandemic around June 2020, she received a text message from the GP and was invited in for a blood test. She wasn't told what the test was for. They only mentioned iron to her and it wasn't discussed any further.
32. She went in for the blood test. Then not long after, she received a further text message asking her to come back in. Subsequently, another followed, saying that she had been sent the message in error and that she did not need to come back in.
33. This point is massively significant and I believe that this was the trigger for her mental health deterioration. The situation was so parallel to what had happened

## ANONYMOUS

previously when she was invited in for tests and subsequently diagnosed with HCV.

34. There was a downward spiral in her mental health at this point. One week after these messages were received, my mother attempted to take her own life. My mum tried to strangle herself, and my dad found her. She was admitted to hospital from June 2020 through to Christmas 2020.

35. She came out of hospital for about four months but was then admitted back into hospital again. The change in her mental health is very stark. I wonder, is this the acute effects of Hepatitis or is it something else? However, I know that the text messages were the trigger.

36. This is a really difficult topic to talk about with my parents, and probably one I'll never get the chance to talk about fully. My Dad was so surprised at how many people stopped talking to him following my mum's mental health decline. He was going through the Covid-19 hell and then this happened to them. Friends and family have turned their backs on the person whose wife was in a mental ward. That has been very difficult for me to see while being so far away in the USA.

37. Being abroad has become really tough on my parents being in this situation. The biggest thing that people need during mental health challenges is support, and I can't offer that. It just doesn't bear thinking about.

38. It is so concerning that nobody at any point ever said, "Your mother is HCV positive and it may have had an effect on her mental health."

39. Mum was always a very happy go lucky person but after my birth she became anxious about things. Of course, there could have been other factors and I am certainly a different person to who I was before my children were born. However, according to my dad, it was very distinct.



40. During my childhood, I can recall a couple of times when my mum had mental health incidents, and she became more and more anxious as I grew up. She became increasingly anxious about her health, and she was really anxious about getting burgled. I found this really unusual and the number of times we found my mother's handbag in strange places around the house.
41. During the lockdown she became more and more anxious. However, it reached a head when she got that text message. There were no signs that my mother would try to take her own life.
42. I remember when my dad called to tell me. It was late evening here. I was so shocked and it really came completely out of the blue.
43. While in hospital she has been identified as having something called 'Cotard Syndrome'. It is a condition where you think your body is failing itself, or that you are dying. It is also known as the 'walking dead syndrome', which is very alarming to hear. This condition was spoken about once, very early on, but then the label has since been replaced with "mental health."
44. Since then, my wife and I have carried out research and have found the link between mental health and HCV. I have asked my dad whether mums previous diagnosis with HCV has been raised with her mental health doctors. I specifically asked him, "Dad, have you told the doctors that there is a link with HCV, and that there could be something they are trying to understand about her brain." We have even helped my dad to write a letter to the doctors regarding this. If I'm honest, I believe the doctors have dismissed this.
45. She has recently received treatment for her mental health, they have tried electrotherapy, however, the brain did not respond to that. I worry this is going to be a long-term thing for mum.



## ANONYMOUS

46. She is currently on medication, but it is just keeping it at bay. She will never be cured. On the other hand, you look and see that she is extremely lucky compared to others. She could have suffered from kidney failure or something, and so many others are not around anymore.
47. The biggest challenge over the last few days has been that mum has returned home. I recently visited her in the U.K and I saw the level of anxiousness that is still there. I left at 9.30am on Saturday morning, and between the hours of 8am and 9.30am, my mother was asking me to check her blood pressure levels. She is convinced that she is not well.
48. My dad has got a big thing on his hands. Part of that is him realising and accepting it, so that the family can put together the mechanism of support for them. The sad reality is that we are staring down the barrel of long-term mental care. I wonder whether my dad is prepared for that, and I do not believe he is.
49. My mum is absolutely terrified of the HCV coming back. The significance of the text messages is so huge and you would have thought the doctors would have known better.
50. I know it is the modern world, but come on. I suppose in some instances it is reasonable and appropriate to text someone like that. But most definitely not in this one. This is the only thing that was a potential trigger to end her own life. Her mental health had already been bad, but then the request for a second blood test really took it to the next level for her.
51. For me, I have the feeling of guilt as if it wasn't for me, my mum would not have required a blood transfusion.

## ANONYMOUS

52. In terms of impact on the family, our children are very alive to the idea of mental health and it is not taboo to them. For a number of reasons, mainly being covid-19, my kids have not travelled back to the U.K to see my mum. However, when they do travel back there is an apprehension that they will see someone very different to who they knew before they came to the USA.

53. From my father's generation there is still the, "Oh we don't talk about that do we." So, it is much harder for him, and he is probably my greatest concern. Not knowing what the future holds, how she will be, whether she will require a specialty caring facility, and that is the hardest part.

54. I hadn't seen my parents since December 2019 until recently. But before all of this happened in June 2020, they were a normal retired couple. Now my dad is very much in the carer role.

55. We have put him in touch with the Hepatitis C Trust but he didn't find them to be much help. This is a contrast with the experience that I've had with them. It has made me question whether he made contact with them, it just feeds back into the HCV taboo and mental stigma.

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

56. My mother had easy access to HCV treatment. As soon as she was diagnosed, the treatment and compensation followed quite quickly. The only regret was that it was in the 2000's rather than earlier.

57. As for emotional or psychological support as a result of the HCV, as far as I am aware, neither mum or dad have had it.

58. If it had been offered, I do not believe the importance of it would have been explained to them.

## ANONYMOUS

59. Doctors did not point it out to her. That is the problem with not accepting that there's a mental health aspect attached to HCV. The link to mental health just wasn't there and even now I do not believe mental health doctors are aware of it.

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

60. When my mother was initially diagnosed, she was contacted by the Hepatitis C Trust and they informed her of the financial support available to her. The Hepatitis C Trust referred her to The Skipton Fund.

61. My mum said that it has been nice to receive the financial support but she has said she's unsure as to why she's getting this money. Being on the outside of things, you do think to yourself that it is a bit strange.

62. Mum received a lump sum payment of £20,000 from The Skipton Fund and a recent lump sum payment of £50,000.

63. She also receives monthly payments of around £1,500 per month.

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

64. For me, the focus of my statement is on the mental health aspect of HCV. The current health considerations that feed in with hepatitis C seem to be focused on the physical consequences. I believe the story does not end at successful treatment for hepatitis C, it can go on and on for HCV victims.

65. At the moment, I feel like I'm one voice that is trying to advocate on behalf of my mother. I want others to realise that there is something beyond this and that it can lead to long term mental health effects.



**Statement of Truth**

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

Signed \_\_\_\_\_

GRO-B

Dated \_\_\_\_\_

18 JAN '27.

GRO-B