

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN7213001

Exhibits: **None**

Dated: 21/12/2022

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 18 October 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1975. I grew up in London and moved to GRO-B nine years ago. My full address is known to the Inquiry.
2. I am married with two children and three step-children. I have worked in the property sector for the past twenty-five years.
3. I intend to speak about my mother, GRO-B: M and her infection with HCV. In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her, our family and our lives together.

4. My father passed away when I was twenty-one-years-old. He cared a lot for my mother and supported her through her ill health. Since my father passed away, and I am their only child, I have cared for my mother. When I moved to GRO-B my mother remained in London to be close to friends. After she had a stroke at her home in London, I moved her over to GRO-B to a care home.
5. I can also confirm that I have not chosen to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am seeking anonymity.
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.
7. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate time frames and detail to matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Affected

8. My mother had a difficult pregnancy with me. Her waters broke early and she was admitted to Edgware Hospital. I was delivered four months premature on GRO-B 1975. The caesarean section was very difficult and a lot of complications arose. My mother had her spleen removed, she lost a lot of blood and so required a blood transfusion.
9. After the operation, I was taken away from my mother, she was admitted into intensive care as she became so unwell and she stayed there for six months. From this point, it pretty much went downhill.

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10. It is strange as I do not know how my mother discovered that she had HCV and so I cannot give a definite point of when she found out. All I know is that one day, it all suddenly became so apparent.
11. All I remember is my mother going in and out of hospital. She would go in every three months, or when she would become unwell. I remember we used to have a family joke that she was going in for her M.O.T and service again.
12. On each occasion that my mother was in hospital she would be there for two or three weeks, and she would come out feeling a lot better. My mother was always so drained as she was always being transferred to different hospitals, and going back and forth every few months. My father looked after her and supported her until he sadly passed away and I then took over.
13. As HCV had always been there when I was growing up and because my father was not a medical professional, to my father and I, it was like my mother 'came' with HCV, and we never thought or questioned where it had come from. There was never an adequate explanation from the clinicians at the Royal Free Hospital about what HCV was, how to manage the infection and how my mother could have been infected with it. I do not think my mum ever really understood what was going on and how the HCV was affecting her. We had all just accepted that she had HCV and never thought more of the infection, other than trying to beat being unwell.
14. My mother was told by the clinicians at the Royal Free Hospital that she had an illness called HCV rather than it being explained that HCV is a virus you can contract from coming into contact with blood from an infected person. As my mother was already very unwell, she thought that she came upon HCV like any other naturally-occurring illness. Also, the doctor and patient culture was much different back then and you would never challenge the advice you were given.

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15. Only over the past couple of years have I looked into this further and I have been able to begin to match the dots to what happened. I finally realised it was the blood transfusion that infected my mother. This was through listening to the news and they were talking about blood transfusions in a certain period leading to infection.

16. There was never any other risk factors with my mother, it is quite probable that the only way she could have been infected is through the blood transfusion. No medical professional has ever sought to find out why my mother was infected, and they made no effort to make the link between my mother's HCV infection and her blood transfusion.

17. As a family, we were never told about the risks of HCV. We had to educate ourselves about what HCV was and what it did to the body. I have never been advised that I should have a HCV test but I assume that other unrelated blood tests would have picked this up.

18. All in all, it seems like my mother was a number and just another patient for the clinicians at the Royal Free Hospital.

Section 3. Other Infections

19. I do not believe that my mother received any infection other than HCV as a result of being given infected blood products.

Section 4. Consent

20. As above, I do not feel that my mother was given adequate or full information about her infection with HCV. She was also never warned about any potential risks of being infected from the blood transfusion.

Section 5. Impact

21. All in all, my mother, despite her ill-health, is a very strong lady and has managed to get on throughout her life. Nonetheless, I think the HCV contributed to further medical complications that my mother endured, detailed below.
22. Mum had a lot of physical and mental stress, and would always be in hospital. To me, I get a text from my pharmacy telling me that I need to go and get my blood checked and even that seems like an effort.
23. To protect me, I know my mother hid a lot of her real suffering. When I received mum's medical records from the hospital on three CDs containing more than six thousand documents on each CD, I began to realise what my mother truly had to go through. I think about how much mental and physical strain these appointments would have put my mother through. To add to this, the Royal Free Hospital is not the easiest place to navigate and is a forty-five-minute drive from where we used to live.
24. Due to the HCV and further medical complications, my mother suffered a lot mentally but she suppressed it and just tried to get by with life. She would never want to bother anyone. Mum always tried to be a very positive person and she accepted her body was what it was.
25. I believe that my mother's infection with HCV meant she was at an increased risk to developing gallstones. At Northwick Park Hospital, my mother had gallstones and therefore had her kidney removed. Throughout this ordeal, my mother was extremely unwell. It was a very daunting time for us as a family as we knew about my mother's history and how weak she was before the operation. My father and I were scared whether she would make it through and thankfully, mum, as the fighter she is, managed to bounce back again.

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26. Before my mother's stroke, there was a decline in her health. Her physical and mental health began to dip. I would go and visit her every weekend when she was still living in London and I noticed her mobility becoming more and more reduced each time. Mum then developed a cyst in her leg and had bad varicose veins, and as a result was in and out of hospital.
27. Mum also became confused about things and her mind slowed down. For example, mum went out to buy a new car and became confused about the car brand, she said that it was an Audi but it was a Volvo. My mother also started having depleted energy levels. A month before her stroke, I had taken my mother to a family wedding in GRO-B and she was only able to stay for a short while. She became extremely lethargic and fatigued, and I ended up dropping her home as she was not well enough to stay at the reception.
28. As a result of the scars from the caesarean section, kidney removal, autopsies and other procedures, my mother's stomach lining has folded three or four times over.
29. About twenty years ago, I remember a letter coming through the post from the Royal Free Hospital, London, stating that they had a new medical trial costing between £20,000 and £30,000 to cure my mother's HCV. My mother showed me the letter and asked me whether I would come to the appointment with her.
30. We went to the appointment, hoping that whatever the clinicians were going to offer would help make my mother better. We spoke to the Professor who went through all the pros and cons of the treatment and my mother decided she would go onto the treatment, which would last from about six months to a year.

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31. Mum was already struggling before the treatment and she became even more unwell during treatment. She was always a very active lady but her battle slowed down.
32. I cannot recall whether or not my mother was informed that she was cured or not. The treatment was just slotted into the many other ingoing and outgoings to the hospital that my mother had to endure. My mother always seemed to have a liver appointment but I cannot tell you what they were concerned about, it may have been for an ongoing problem or treatment.
33. At some point, I think there was a mention of cirrhosis by the hospital as I remember reading my mother's hospital letters. Mum would always complain and worry about the number of biopsies that she used to have. The biopsies were extremely painful and she had to undertake quite a few.
34. After the treatment had finished, I think my mother received a letter saying that she was cured of HCV and the treatment had worked, however I was never convinced as she remained so unwell. I do not truly know what the current situation is with my mother's HCV as my mother receives no aftercare from the hepatology department now at all. There was aftercare after my mother had her stroke but nothing for her HCV.
35. HCV had a wide impact on my mother's family and social life. There were a lot of things she could not do as she felt too unwell. Mum would also always have to cancel plans because of appointments. My mother is a very sociable person, and she always enjoyed getting out of the house and doing something active. Although, none of this was easy for her.
36. When I was quite young, my mother had to stop working. This would have definitely played a negative impact on her mental health as she loved working with her colleagues.

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37. My mother loved travelling but her ill health would stop her from being able to go away. We would sometimes go to the US as a family but my mother was always worried that she could fall ill if she was abroad and that it would be very expensive if she did so. Mum would only have made plans to travel if she knew in herself that she would be okay for the next two weeks or so.
38. After my father passed, my mother wanted to move closer to her brother in the USA. However, due to all her medical conditions caused by her HCV, going to America would have been untenable as all the medical care over there is private and she would have to pay for everything.
39. I bought her a retirement flat in London when my father died. I always told her that there was space for her in my home but she wished to stay in London with her friends.
40. After my mother's stroke, my wife and I were both driving to London from GRO-B as much as we could and we were often there for four days a week for the space of five months. Thankfully, I had the support of my wife when my mother had her stroke.
41. The doctor explained that my mother's left side was going to remain paralysed so I made the decision to not bring her back to her home in London but rather to bring her closer to me in GRO-B. Although she had wished to stay in London, it would not have been possible for my mother to stay in London as I would not have been able to look after her.
42. Moving away from London was particularly hard for mum as she was taken away from all her friends and her entire social life. To make this even worse, despite visiting every day before COVID-19, we were no longer able to visit her when the pandemic began. As a result of my mother being stuck in her room during the pandemic, her dementia came early and now she is suffering really badly from it. She was very strong beforehand.

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43. Looking back, my mother has never been a very affectionate person and never really showed her love. I feel that due to my mother's mental and physical hardship throughout her life derived from the HCV, she suppressed a lot of her emotions. Despite adoring us, my mother would never express how she felt. It has always been strange for me when at a friend's house or my in-laws, who are very affectionate and loving.
44. The ripple effect of my mother's infection has had a massive impact on all the family members. I look back and see my father was under immense pressure looking after my mother. As I was young, I had a lot of interest in going out and my dad was putting all his energy and time into caring for my mother. My father was also trying to keep the roof over our head. As my mother was always in and out of work due to her ill health. My father had two jobs; he worked in a factory and as a painter and decorator. Looking back, I can see how my dad dealt with my mother's ill health and how he committed his life to helping her.
45. My father was working so hard to keep the family afloat and was also under such great pressure to provide for us all. I think all of this contributed to his heart attack. My father was as fit as a fiddle before he suddenly died from a heart attack. If I had to bet on someone dying first it would have been my mother due to her ongoing ill health.
46. All of this has definitely had a negative impact on me as well. Despite wanting to go away for university, I ended up going to university in GRO-B so that I could be around to help my father with my mother. I would also often miss university as I had to take my mother to the hospital or take care of her.
47. As many young people do, I wanted to leave the family home and develop myself further. Nonetheless, I am happy that I got the time to spend with my mother, but I do feel as if I have missed out on a lot.

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48. Like my mother, I also had an opportunity to go to the USA. My uncle wanted to partner with me to buy a motel. My mother and father wanted me to go but I just felt I could not because of my mother's health. In hindsight, I am glad it that never happened, as everything happens for a reason but at the time it was very difficult for me.

49. Even recently, I often have to call in sick from work, just so I can be there for my mother. When I used to work in London, I would have to rush home if my mother became unwell.

50. I feel my children have also been impacted by my mother's ill health. My mum used to pick my daughter up from nursery and they had a close relationship. My daughter would often see my mother going in and out of hospital, and at times, an ambulance turning up at the house. When my children see my mother at the nursing home, they find it very upsetting. It is not nice for them to see their grandmother go through so much.

51. In terms of stigma, I would not have been aware of the stigma associated with HCV. As my father and I were under the impression that HCV was something you were born with or something that progresses over time - we just thought my mother had fallen ill.

52. The more and more I talk about what happened to my mother, the more guilty I feel. I am kicking myself and I am annoyed as I feel that I should have paid more attention to what was going on with my mother's health, but I was young at the time. In fairness, as mentioned, we were also never given adequate information from the medical professionals so I did not know how unwell my mother really was.

Section 6. Treatment/Care/Support

53. I am unsure whether my mother faced any difficulties or obstacles in obtaining treatment, care and support in consequence to being infected with HCV.

54. My mother has never been offered any counselling or psychological support. I feel that psychological support would have helped my mother a lot when working through her emotions.

55. Psychological support would have also helped my father understand more about my mother's situation and how to help my mother cope better.

Section 7. Financial Assistance

56. My mother and I have not been in receipt of financial assistance from any of the trusts or schemes due to our difficulties detailed below.

57. Whilst it was not particularly difficult to obtain my mother's medical records. I was sent three password protected CDs with over six thousand files in each. I am struggling to review the high number of files and this has made it even more difficult to obtain financial support.

58. It has also been very difficult to get the EIBSS form signed. My mother has not seen a hepatologist whilst living in GRO-B and they have said we need to ask the Royal London Hospital as she was under their care. But then the Royal Free have said they cannot sign the form as my mother has been discharged from their care.

59. I also tried to go about the private route to see the consultant who treated my mother at the Royal Free, but the initial conversation would have cost £500. My mother's GP has referred her to a hepatologist in

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GRO-B but we have been told that we could wait up to six months due to the current delays in receiving NHS treatment.

60. Further to this, my mother's GP records only go back to around 2014 and so her blood transfusion in 1975 is not detailed.

Section 8. Other Issues

61. Overall, I would like someone to take responsibility for what happened and explain why it happened.

Statement of Truth

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

Signed

GRO-B

Dated

21/12/2022