Witness Name: GRO-B
Statement No.: WITN2828001
Exhibits: WITN2828002-WITN2828008
Dated: 9 December 2019

WRITTEN STATEMENT OF GRO-B

INFECTED BLOOD INQUIRY

Section 1. Introduction

1. My date of birth is GRO-B and my address is known to the Inquiry.

2. I have four siblings. I recently lived in GRO-B but moved back to London in 2019.

3. I am writing this statement in memory of my father, GRO-B: F whose date of birth is GRO-B

Section 2. How Affected

4. My father had a duodenal ulcer which resulted in complications and he had an operation called a highly selective vagotomy, in June 1974 at the GRO-B GRO-B Hospital **(WITN2828002)**, which required a blood transfusion on an emergency basis. He was infected with Hepatitis C (HCV) by this blood transfusion.

5. Ever since I was a baby my father has always shown me the huge scar on his stomach and told me the story of his operation and the blood transfusion but we did not know he had been infected.

6. As far as I am aware, and from my father's statement, he was given no advice on the risk of infection before being given his transfusion.

7. My father passed away on GRO-B of liver cancer. He previously submitted a witness statement for the Inquiry on GRO-B please see this statement GRO-B for more details of his infection with HCV.

8. My father did not find out that he was infected with HCV until 2013. He was told by his GP, Dr GRO-B Dr GRO-B called him to come to the surgery, and when he came in he was told of his infection.

9. By the time he found out he was infected, his liver was already severely damaged. He was referred to Homerton Hospital for tests and it was determined that he had cirrhosis of the liver.

10. My father was in shock when Dr GRO-B told him he had HCV. I believe he felt that Dr GRO-B had failed him because he had attended the surgery so often complaining of nausea, shortness of breath, back and stomach pain, and

dizziness, but nothing was ever diagnosed. He lived with HCV without knowing for nearly 40 years, and by the time it was diagnosed there was little he could do to repair the damage already done.

11. I also find it inappropriate that my father was not told of his infection as soon as possible because HCV can be passed down to children. I have been tested, however, and tested negative.

Section 3. Other Infections

12. I do not believe my father received any other infections apart from HCV.

Section 4. Consent

13. I believe that the government chose my father to be a test. He was very trusting of the medical system and the system failed him.

14. I believe that the people who were affected by this tragedy were all tests for research. My father went to the hospital all the time and always felt that the doctors were very interested in conducting tests and were discovering things about him but he was never given information about what tests were being done and why. I believe information was withheld from him intentionally.

Section 5. Impact

15. The mental and physical effects of HCV caused my father's health to decline over the years, and eventually killed him. In the years between his diagnosis and his death, his life was weakened in many ways mentally and physically, from going to the shops to playing with his grandchildren, to using the toilet, to sleeping at night.

16. Mentally his diagnosis caused him to suffer from knowing that this disease might take his life. Can you imagine finding out that this is what is going to happen to you because you trusted in organized government healthcare? This has affected every single one of his children, his grandchildren, his wife; everyone. But mostly my father.

17. As a result of his HCV infection my father developed a number of chronic illnesses, including but not limited to prostate cancer requiring 5 months of intense chemotherapy, liver cancer, severe urinary tract infections, high blood pressure, diabetes, and bad circulation in his limbs.

18. My father was treated with Harvoni and ribavirin for the HCV in 2015. The treatment lasted 12 weeks The treatment was successful in clearing the virus; however, the extensive damage done by the virus could not be reversed.

19. During the treatment, my father had serious side effects. He was depressed, got urinary tract infections, and had constant flu like symptoms, including being sick, a high fever, feeling lethargic and having trouble sleeping at night.

20. He did not have any significant difficulties in accessing this treatment, but I find it unacceptable that he had to wait two years from his diagnosis to get treatment, as he had already been infected for so long.

21. My father was a loving husband, father, grandfather, great grandfather, friend, uncle, brother, and pastor. He gave so much to people mentally and physically. Before he became ill he was a very active family man. He would run around with the children, carry babies, and generally had a lot of energy. As he became more and more ill, we could see that his energy was really depleted. He never felt good; if it seemed like he did, we knew he was masking the pain. As his

illness progressed he stopped being able to go out even for a short walk, and everyday things like cooking became very hard for him. His interaction with the family was limited, as he didn't have the energy to play with the children interactively, and could only play sitting down. Toward the end, you could really tell that he was dying, and that it was causing him pain.

22. The impact that this has had on me physically, mentally and emotionally is that I am weak and suffer from anxiety and depression. I am the youngest child of my father, and I am sad that I didn't have as long with him as my siblings did before he was taken away from all of us. We love my dad so much; he was the most caring, loving, inspirational man that I have ever met, and I feel the NHS has destroyed that by taking him from us.

23. After my dad's death I have really lost faith in the NHS. My dad went to doctors to get treated and helped, and toward the end we really felt that the doctors' aim was just to get him out.

24. The stigma of having HCV has affected us. When my father was being treated in hospital, we felt that people higher up in the hospital were aware of HCV but some nurses and doctors still thought they could catch it from him. My father generally felt he could be open about his infection, but did feel embarrassed to admit that he was infected by the NHS.

25. My family and I will never be the same as we were before my father died. We are completely broken. My siblings and step mother are still very depressed and having trouble coping. It breaks my heart that my step mother has been left without a husband, and we don't have a dad. I was pregnant when he died, and he knew that he would never be able to meet his grandson.

26. My father was the rock of our family and the NHS have taken him away. He is still the strongest person that I know to go through as much as he has for so long. I will make sure that justice will be served. Before my dad died, during my last conversation he told me to follow up with the Inquiry and make sure justice is done for him and the family, so that's why I am making this statement. I will be fighting for my father and his legacy.

27. Before I was born, my father worked as an electrician at BT, but he had to retire eventually due to his ill health. After that he had no source of income, where before he had been the main source of income for our family. We went form having a full time salary to rely on to going on benefits. We lost our house, our savings, and struggled to pay rent. It was upsetting for me as a child to have to rely on the state, when we knew our father had been hard working and would have kept working if he could, and has had knock on effects on all of his children's finances.

28. My schoolwork was also affected because I knew that my father was ill and there was nothing that anyone could do. In secondary school I lost focus because of this, and though I managed to pass, I did not get good grades. I did go to college and get AS levels, but did not manage to get full A levels. I couldn't focus on choosing a career, and felt like I was just floating. Eventually I went to several community colleges and did short courses in music management and makeup artistry. I then ended up moving to America to work as a makeup artist about 9 years ago.

29. I have just moved back to London after my father's death this year to help the family cope and sort out paperwork. I never wanted to come back to the UK, and if this had not happened I would have remained living and working in **GRO-B** I have a loyal client base there and felt settled. However I am committed to ensuring justice is done for my father and will stay here as long as I need to.

30. I have not worked since about 4 months ago, due to assisting the family when my father was very ill, travelling here and then having my baby about GRO-B ago. I think I could work here if I take time to develop my contacts, but that is not what I want to do. I spent a lot of time, money and energy ensuring I could stay in the US if I wanted, by getting and renewing visas, obtaining a green card and building up my client base. I would like to return there if I can.

Section 6. Treatment/Care/Support

31. My father did not face any difficulties obtaining the treatment. He had difficulty obtain treatment at the right time! It could have prevented all the other illnesses that followed.

32. He did not receive any counselling or psychological support.

Section 7. Financial Assistance

33. We did not find out about EIBSS financial assistance until 2018. My father found out about it from a news programme, and I looked into it and applied for him on 9 May 2018.

34. We found the process of applying for support difficult because there were a number of preconditions, which required locating documents in medical records, and there was no one available to help us. Once we had completed the application form, it then took a very long time to get my father's doctor to stamp the form so we could send it in. This delay is significant when you are applying for support for a very ill man, whose life would not last much longer.

35. My father's application was rejected because there is no proof of his transfusion in his medical records **(WITN2828003)**.

36. We submitted an appeal on his behalf on 18 September 2018, but this was also rejected. The rejection letter from EIBSS states as follows **(WITN2828004)**:

> *The Panel noted that the further records that you provided confirmed that you underwent a highly selective vagotomy procedure in June 1974 for your duodenal ulcer, after which your abdominal wound healed well. Having considered the further evidence provided, the Panel's view was that this surgical procedure would be unlikely to cause sufficient bleeding as to require a transfusion at the time. This information in conjunction with the lack of supporting records confirming the transfusion meant that the Panel were unable to be satisfied, that it was more probable than not, that your Hepatitis C infection resulted from qualifying NHS treatment.*

37. This is despite my father including with the appeal a letter from Consultant Physician Ian Ewing from 4 May 2018 confirming that he is "aware of no risk factor other than iatrogenic transfusion of blood for your previous history of chronic hepatitis C infection" **(WITN2828005)**.

38. My father exchanged emails with someone called Chris Boddy at EIBSS asking if his appeal could be reconsidered, and Mr Boddy responded in April 2019 saying that his appeal could not be reconsidered in light of new evidence and he would need to submit a new application if he wished for that evidence to be considered **(WITN2828006)**.

39. My father then wrote back to Chris Boddy on 28 April 2019 asking for assistance in submitting a new application and documentation of the reason for rejecting his appeal, and emphasising that the matter was 'very time sensitive', as he knew he would not live much longer.

40. A Rebecca Kennedy from EIBSS further clarified in an email to my dad on 1 May 2019 as follows **(WITN2828007)**:

> *The appeal panel is made up of medical experts in the fields of liver disease, blood transfusion services as well as a general medical practice with a legally qualified chair. The panel must base their decision on their own knowledge in their field that it is more likely than not, the infection was caused directly through treatment with NHS blood, blood products or tissue before 1st September 1991 therefore we are unable to provide criteria or a policy document.*

41. I am frustrated that my father was denied assistance. I understand that the operation he received doesn't usually require a transfusion, but that does not mean he didn't receive one. His operation was very serious and left a large scar; it may be that in a more straightforward case a transfusion would not be required, but he certainly received one.

42. My father exchanged further emails with Rebecca Kennedy, despite his rapidly declining health. He asked again to see EIBSS policy documents, and on 13 May 2019 Ms Kennedy responded **(WITN2828008):**

> *We do not hold criteria or policy documents.*
>
> *Originally your application is assessed by a medical assessor. Due to the application not being approved, the application is then presented to the appeal panel. The appeal panel is made up of 5 individuals who review each appeal and does not include any of our medical assessors. Our medical assessors and appeal panel must base each decision on the balance of probability and are medically trained within relevant fields.*
>
> *If you can provide additional medical evidence or if you have any queries related directly to your appeal, we can investigate your requests further.*

43. I think it is shameful that my father was not able to receive any assistance to make his life more comfortable in his final months, to cover his funeral costs, and to compensate his family members who have had to give up work to care for him. It is even worse that this was due to the bureaucracy of the NHS delaying in stamping his form, and EIBSS rejecting it without considering the available evidence that he his only risk factor for HCV was his blood transfusion.

Section 8. Other Issues

44. My father had to fight to access his medical records when he was trying to apply for EIBSS assistance. The doctors were making him go through hell to get that information, which he should have been entitled to for free. In the end I had to email them about it, and then they sent it to him in next day. Why were they making it so hard to get information that he is entitled to, knowing his circumstances, when it was clearly easy enough for them to provide it to me when I asked? Hiding the information or creating obstacles for people trying to obtain it makes an awful situation even worse for everyone who has already been made ill by the NHS.

45. I think my father should have been entitled to a lump sum for what he has been through. However, it is too late for him now, and any amount of money provided to the family cannot give him back to us. We would all much rather have him back than take any sum of money. However, at the very least, I think my father's estate should receive compensation for the fact that he had to live with this disease and the associated pain and suffering for his whole life. I also think the family should be compensated for funeral costs, as well as our pain and suffering from watching our dad deteriorate in that way. The experience was extremely painful. We also paid some private medical expenses to obtain tests and opinions before it was too late, and travel costs to hospital.

46. I feel very strongly that the government has failed us. The fact that the government even failed to provide us with information about what happened early enough for people to get treatment demonstrates how unreliable and untrustworthy this whole journey has been. My father even contributed to working for the same government that failed him. It is heartbreaking to know that this is what the government has done to him and so many others, this is

diabolical because the failure and carelessness of the NHS has led to so many health issues that my father can never get back. They have taken his life for granted all in the name of science and recklessness. This has made me as his daughter want to fight for him because nobody that has not got through what my father has, does not understand. My father was taken away from us because of this scandal.

Statement of Truth

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

Signed GRO-B

Dated 09/12/2019