Witness Name: GRO-B
Statement No.: WITN1969001
Exhibits: WITN1969002–WITN1969005
Dated 23 August 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B. I am widowed and I live by myself in GRO-B Essex. My address is known to the Inquiry. I have four children: two girls and two boys. I have seven grandchildren and two great grandchildren. I used to live in GRO-B before moving to GRO-B with my late husband 20 years ago.

2. I have been retired since 2019. I spent most of my career working in hospital blood labs.

3. I was infected with Hepatitis C (HCV) in 1991 following a blood transfusion.

Section 2. How Infected

4. In February 1991 I was admitted to the Royal London Hospital for a hysterectomy to help improve my painful periods. My medical records show I was in hospital from 5 February until 20 March 1991 and then from 25 March

until 3 April 1991 [**WITN1969002**]. The Royal London Hospital was also where I worked at the time in the blood labs.

5. Unfortunately, the surgery did not go to plan and as a result, I had to have a blood transfusion. I was transfused with 12 units of blood from 12 donors [**WITN1969003**].

6. In around May 1991, I was admitted to hospital again due to surgery complications and symptoms of hepatitis. While I was recovering in a ward I overheard – by pure chance – a nurse saying that I had tested positive for HCV. The next time the doctor came round, I broached this with him and he confirmed I had HCV. At first, I thought being positive just meant I had some immunity. I knew, for example, that I was immune to Hepatitis B as I'd been vaccinated because I worked in the NHS. Then I looked at my medical notes at my bedside and realised that in fact I had a viral HCV infection. My hands were trembling. If I didn't have a medical background through my work in the blood labs, I would not have cottoned on having overheard the nurses' conversation and would have remained in the dark about my status.

7. After my diagnosis, I asked one of my colleagues from the lab to look at the records of my transfusion. I recall her telling me that I had been tested for HCV before and after my hysterectomy as part of routine blood testing, and that this confirmed that I had contracted HCV as a result of the transfusion I received. I am aware that there is a letter within my medical records dated 3 May 1991 that states that I had not yet been tested for HCV, but I recall being told I had been tested at the time of the procedure [**WITN1969004**]. I am therefore disappointed that I only found out about my HCV status three months after the surgery, and then only because I overheard a nurse.

8. At the time of my diagnosis, little was known about HCV. I ended up getting very ill a few months after my diagnosis, which was very scary. I had pains in my fingers and toes and it felt like I'd become an old woman. I was only 39.

9. I can't blame the hospital staff, they were just doing their job. They were not screening for HCV in blood donations until September 1991 so the blood I received wouldn't have been screened. I know this from my experience working in the blood labs. Being a medically trained professional, I know that you can only work with what you know and with the information presented to you.

10. I was not told of any risks of blood borne diseases through blood transfusions. Even as a medical professional, I was not aware of the particular risks of being infected with HCV. We knew very little about it at the time, and all our concern was directed at Hepatitis B and HIV.

11. At the time I received the transfusion, I wasn't the full ticket, to be honest. I'd had complications from the procedure and could not properly process information given to me by the doctors. My husband was not at the hospital either, so he couldn't ask the doctors any questions on my behalf. I do feel I was treated without being given adequate information. I wonder, though, how much the person who decided I should have a transfusion knew about these risks themselves.

12. In 1994, I requested a look back to try to identify the donors of the blood I was given during the hysterectomy and whether any of them had later tested positive for HCV. I knew this could be done because of my role in the blood labs and I needed closure on how I became infected. In a letter dated 8 February 1995, Dr Angela Gorman states that of the 12 donors whose blood I was given, one had tested positive for HCV in 1993 [**WITN1969003**]. It was therefore assumed that it was that donation that had given me the HCV infection.

13. I was not given any information about how to manage my HCV infection at the time of my diagnosis or in the years afterwards. I researched it, using medical books and the internet. Without a doubt, if I hadn't had any medical knowledge, I wouldn't have known anything about how to avoid infecting others or how to manage my condition based on the information provided to me by doctors. Even if little was known about HCV at the time of my diagnosis, I feel I should have been updated as soon as the medical community did gain this knowledge.

14. I am very disappointed with the way I discovered I had HCV. I feel I should have been told as soon as doctors knew I was infected, and I believe I should have been told in an official appointment with a doctor, rather than overhearing such significant information by chance. Any patient should be told if they have tested positive for a disease. It is not something that should be kept secret.

Section 3. Other Infections

15. I believe I was only infected with HCV.

Section 4. Consent

16. I do not recall giving consent to receive a blood transfusion. It was an emergency transfusion during surgery because I had haemorrhaged. I accepted at the time that I simply needed the blood. I regret having the transfusion, though. It had ruined my health and I would not have consented to it if I had known the risks.

Section 5. Impact

Health issues

17. I have experienced numerous health issues as a result of being infected with HCV.

18. In 1996, I went to see the HCV specialist who recommended I have Interferon treatment. At that point, I would have agreed to try anything. At the time I thought HCV was a death sentence. I feared not seeing my five-year-old son grow up.

19. The treatment was terrible. After I had my injections, I couldn’t do anything. My husband had to take time off work to care for me. All I could do was lay in bed trembling, and it felt like I had a terrible flu. I felt like ice was moving through my body. The feeling still haunts me.

20. The worst part of being on treatment was that it was that it made me feel suicidal. I remember telling my husband and the doctor over and over that I wanted to kill myself. I was off work for four months. My husband had to stay with me constantly to ensure I didn't harm myself or our son. Sometimes it felt like I was on drugs, like I was someone else.

21. My doctor took me off Interferon in June 1996 after twenty weeks of treatment [**WITN1969005**]. He did this for two reasons: my suicidal thoughts, and the fact that the treatment was not working to eliminate the HCV. I still have the viral HCV infection today.

22. I was never advised of the risk that Interferon would make me feel suicidal. In the desperate state I was in, I think I would have accepted the treatment regardless, but I believe I should have been warned of this potential side effect by doctors.

23. Shortly after I stopped treatment, the suicidal thoughts went away, but I continued to feel depressed. I fell into depression when I was first diagnosed with HCV. For decades I felt embarrassed to say anything to doctors. Over ten years ago, my GP noticed that I was down and offered me anti-depressants. I declined because of the stigma I felt there is against people who take those kinds of medications. I also worried about taking them because when you apply for a job within the NHS, they ask you about things like that and I didn't want to lie.

24. Eventually, in 2018, my depression got so bad that I agreed to start taking antidepressants. Since I've started taking them, I feel like I'm in a new world. I feel much better.

25. My experience on Interferon changed my life forever. I now have so much anxiety around HCV treatments that I've never tried anything else. I have been offered treatments several times, including a trial treatment at the Royal Free and a totally new treatment offered to me just last year. Every time a treatment is offered to me, I have a panic attack; I start crying and shaking even just

thinking about trying a treatment. I even struggled to talk about HCV treatment while preparing this statement. I feel sad that my anxiety which developed as a result of my treatment experience in 1996 continues to prevent me being able to accept medication that could clear my infection.

26. I have had a few major HCV flare ups. The last one was in 2019. I got up for work and started vomiting. I still went into work, but didn't feel any better so I had to go to A&E. They discovered that my viral load was very high, and that was causing my sickness. That was my last day of work, I never went back.

27. I've also developed arthritis as a result of my HCV. It's reactive arthritis, which means that it comes and goes, but when it comes I am crippled by it. It's led me to fall over in the street, for example. I take naproxen for the pain, and I have other medications to counter the side effects of the naproxen.

28. Luckily, despite never clearing the HCV infection, I have not developed cirrhosis. I have liver scans regularly and they haven't been too bad. I eat a very good diet and I don't drink much.

29. I do not feel that there are any treatments for HCV or other conditions which ought to have been offered to me but were not. Due to my bad experience on Interferon and the anxiety it has left me with, I have not felt able to explore treatment options with doctors.

30. I have had problems accessing dental care. Two years ago, I had six teeth extracted privately and I paid £900. I was supposed to have a monthly allowance through the NHS for dental treatment, so I believed I would be reimbursed. I filled in the form and sent it in, but they refused my application and asked for further evidence. I didn't have the energy to seek out evidence so I just left it and was never reimbursed.

Family, social and private life

31. HCV had a significant impact on my relationship with my husband. He had to take a lot of time out of work to care for me, as I mentioned earlier in my statement. Before the look back confirmed that I was given contaminated blood, I also worried that my husband might have been unfaithful and I fear he worried I had been unfaithful. If I had not had that confirmation, I believe we might have struggled to maintain our relationship. We are Christian and it would have been hard to move past worries that one of us had been unfaithful.

32. The impact on my children has been huge. When I was diagnosed, my children were aged 20, 17, 15 and 5. I have been unwell for a large proportion of their lives, and I feel particularly sad for my youngest son who has had a sick mother for the majority of his life. He missed out on the mum I was for the older ones. I remember once when I was in hospital in 1991, my husband took him to come and visit me in hospital, and my son said “you made my mum sick” to one of the doctors.

33. My children worry about me a lot and have done ever since I got sick. Between them, they will come and visit me two or three times per day. They call me constantly to check I am ok, particularly since my husband died in 2009.

34. I don’t have many friends. This is partly due to the environment I grew up in. I am from a Christian home and we grew up mostly socialising with family. However, I do have a small circle of friends. Unfortunately, my depression has stopped me seeing friends for long periods. When it was bad, I wouldn’t leave the house. Since being on anti-depressants, my social life has improved.

Stigma

35. Only my immediate family and doctors know about my HCV status. Being able to share this part of my life with others has never been an option for me. My parents are from Jamaica. If I was to tell anyone outside of my immediate family about my HCV, word would get around the West Indian community locally, and

I would be seen as a disgusting leper. I didn't even tell my parents about it, they only found out because I was very ill at one point and they visited me at the hospital.

36. As a result of this stigma, HCV is simply not something I have ever been able to talk about. I knew this would be the case from the moment I was diagnosed. The stigma within my community persists, and I actually think it is worse now than it used to be. People can't even talk about having diabetes without being shamed. I once knew someone within my community who contracted HIV and I witnessed them being cast aside by my friends and family. If I told people about my HCV, I'd be shunned. I would stop being invited to things and my friends would stop talking to me. This is something I have grown to accept over time, and not something I expect to change any time soon.

37. My children also experience this community stigma as they are unable to share their stresses about my illness with others.

38. I have not experienced any stigma from doctors. My GP has been very sympathetic, and so were doctors at the Royal London.

Work and education

39. My HCV effectively ended my career. In 1997 I took a kind of early retirement because I was too ill to work. In 2008 I began working again and I have been able to return to work for short periods at various hospitals but I have been off sick more than I have been at work. During my better periods health-wise, I have always worked competently and believe that if I had not been infected with HCV I would have had a successful career. Unfortunately, my sick record has always been poor which impacted my career prospects.

40. In 1997 I decided to go back to education. I studied business and finance at college part-time in 1997-8. I then did a science and computing foundation course at university, before going on to complete a bachelor's degree in

Biomedical Sciences in 2006. I was grateful for support from the university's disability services. Without that support, I wouldn't have been able to complete my degree.

41. I retired in 2019 after the incident I mentioned earlier in my statement when I became very ill at work due to my viral load. I feel my career has really suffered as a result of my HCV which makes me feel sad. I know I could have ended up in a senior post but because of my sickness record could not have applied for more senior positions.

Finances

42. HCV has had a terrible impact on my finances. As I have been on sick leave and medical retirement for large portions of my career, I have lived on disability benefit and my husband's salary. The situation was even worse when my husband acted as my carer as he was self-employed so was earning nothing when he took time off. There have been a few times when we were threatened with having our house repossessed. This put further strain on our relationship. Now, my pension is not as good as it would have been had I been able to work as I had been pre-HCV diagnosis in the NHS.

Section 6. Treatment/Care/Support

43. I have had counselling, but I paid for it myself. My GP suggested I go to counselling for my depression and gave me a telephone number and a leaflet. I phoned them, they assessed me, and they told me I could benefit from psychological support. I was allocated a counsellor who I saw every two weeks for a few months. I tried to recoup the money but the form was too complicated.

44. I definitely benefitted from receiving counselling. I have thought about going back but finances are an issue; I can't afford it. I would take the opportunity if free counselling was available.

45. I have never been informed of counselling available to people with HCV or as a result of being infected with HCV through the Inquiry. I have since been informed about potential options available to me from my solicitors.

Section 7. Financial Assistance

46. I applied for Skipton in 2007. I was told about the fund by one of my doctors. I got a lump sum payment and after a while also began to receive the monthly payments. I am glad to receive the payments, but they are nothing in comparison to what I've lost.

47. Sometimes I fear that the monthly payments may one day stop. I hope that this Inquiry will go some way to preventing that from happening. At the moment, it all just feels like a nightmare that never ends. For example, I worry about who would care for me if I went into treatment now my husband has died; how would I pay for care costs?

Section 8. Other Issues

48. I attribute blame largely to the Government. I do not place blame on the medical professionals who treated me back in 1991 as I believe they were acting on the information available. I do, however, believe I should not have found out about my diagnosis through overhearing this information. I would like for the NHS to ensure this does not happen to others.

49. I would like for the Government to tell us what they actually knew and when, as I fear there has been a big cover up of this scandal. I also want to know why it has taken so long for this to come before a public inquiry. I have had HCV now for over thirty years and I cannot understand why in all that time there was no investigation into what happened. It would be a bonus to receive compensation.

50. I also think it would be good for there to be a public information campaign to educate people about what HCV is and how someone might become infected

through blood. I do worry this may have a limited impact on communities like mine, however.

51. My solicitors were only able to access just over 300 pages of my medical records. I had previously accessed information about the look back investigation so was able to pass these onto my solicitors. These documents were not included in the records provided to them by the Royal London Hospital.

Statement of Truth

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

Signed GRO-B ....

Dated 23.9.2022..........