Witness Name: GRO-B

Statement No.: WITN3916001

Exhibits: WITN3916002 - WITN3916004

Dated: 16 November 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

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

Section 2. How Infected

2. I was knocked down by a car on 7 August 1982, when I was 14. I spent three months as an inpatient at Royal Surrey Hospital in Guildford afterward, the first two weeks of which were in the intensive care unit. My friend who I had been with at the time of the accident did not survive.

3. I was not informed of what surgical interventions I would be having at the time as I was unconscious and underage, however I understand that I had an operation upon admission to hospital on 7/8 August to repair my broken femur and about 16 to 20 stitches to repair the lacerations on my left leg. I also had a

severe head injury; I remember I wasn't allowed to see a mirror for weeks, as my head had swollen to twice its normal size. There are contemporaneous letters confirming the surgeries I had. **(WITN3916002).**

4. I was not aware at the time that I had received a blood transfusion during my operation. I do not believe my mother was given this information either; I am sure she would have included this detail when recounting the story of my accident as that is the sort of person she is to ensure to include all drama. I am now estranged from my mother so am unable to ask her what information she was given, but it is very likely to be none.

5. I have always wanted to donate blood since the accident. Although I did not know I had received blood whilst in hospital, I had been in hospital for three months and wanted to give back to the NHS for helping me recover. I first attempted to donate blood in my early twenties, but was told I could not because I had had an operation in 1982 and might have had a transfusion. I was not given any more information than that and did not think about it any further. I then tried again about 10 years later and was refused on the same grounds.

6. This really frustrated me as I very much wanted to give blood, so I contacted the Royal Surrey Hospital to ask if I had had a transfusion during my operation. They told me that in order to obtain a copy of my records from 1982 I would need to pay £50 and fill in a form. I could not afford that at the time, so decided not to complete the request.

7. In 2018, I was working as **GRO-B** for a GDPR project. I was looking into the GDPR regulations, and realised I could now ask for copies of my records and they would have to be released to me. I contacted the Royal Surrey Hospital to ask for my records and they replied that there were no records of this event **(WITN3916003).** I then contacted the Blood Transfusion Service, and they also said they no longer had paper records and my operation was too long ago to be on their computer system. The person I spoke to told me that I was probably fine, and I should just give blood anyway as it will be

tested before being given to anyone else. I had never previously understood what a transfusion meant, all I knew was that it was a barrier for me donating blood.

8. I assumed from that conversation that the need to find out if I had had a transfusion was simply a tick box exercise, so the next time I tried to donate blood, in May 2019 I answered the question "Have you ever had a transfusion?" on the donation form with "No" instead of "I don't know". I was then permitted to donate and after giving blood was told that I would receive a letter explaining how my blood had been used

9. A short while later, I received a letter from the Blood Transfusion Service which stated that my blood could not be used because I had Hepatitis C ("HepC").

10. I found the letter in my postbox when I got in from work and due to the total shock I had to cancel a planned meal with a friend in 2 hours' time. I was astounded, and could not understand how this had happened. I went straight to the computer and googled HepC. I was shocked and stressed about what was happening.

11. The letter provided me with a phone number to call if I had any questions, so the following day I phoned the number. I spoke to a woman who asked if I'd had any tattoos and repeatedly asked me if I was sure I had not taken any drugs. She also told me to be very careful who I told because there is a real stigma attached to HepC. It really freaked me out – I had no idea why she kept asking me about drugs.

12. I rang my Surgery and asked for an urgent GP appointment to discuss my diagnosis. My doctor was very professional; she arranged for all the necessary tests. I came back to the surgery for my test results and she confirmed I did have HepC and gave me a sheet of paper with printed notes on it. I asked why she had not tested me for HepC earlier, and she replied that I did not find the criteria. I asked why not, as I had had many medical interventions over the years, but she had no answer to this.

13. My initial reaction to my diagnosis was shock that I had been informed by post. After speaking to the Blood Transfusion Service and being told of the stigma, I felt dirty. I felt so dirty and in shock, I did not want to tell anyone about what was happening. I did share the detail with my psychotherapist as I needed support. However, I did not share the details with my dad and step mum until I had something to tell them as I did not know what was happening and what to tell them.

14. I was very frustrated that I could have found out so much earlier, and concerned that I had been turned away from donating blood a couple of times over the past three decades, but had never been advised what a transfusion meant and that it had a bearing on my health. Why would I?

15. As I began to understand the implications of having HepC, I became worried about what my future would look like, how long I would live and became very upset that I may miss my godson growing up.

16. Through my online research I found the Hepatitis C Trust, and phoned them for advice. The woman I spoke to was very helpful. I asked what would happen next and she talked me through it, told me what further tests I would likely have and what would happen. I found this comforting as the journey of waiting to be referred to the hospital was not coming quick enough. I now knew I would have to have a fibroscan, and lots of blood tests which was hard to get my head around.

17. I do think I was given adequate information about my infection at the time of diagnosis. At such a stressful time, I would have been unlikely to take in much detailed information anyway and I knew I would search the internet when I got home. I filled in the gaps and unknowns with online research, and through this, found out about the Infected Blood Inquiry. I had no idea anything like this was happening.

18. I do think that I should have been tested and diagnosed earlier. My GP had a record of my operation; I feel she should have known I was at risk and done tests. I am really frustrated that I was not told of my infection earlier. I was told I could not give blood on two occasions but not given any further information about the risks of having a transfusion then. If I had known that I was at risk 20 years ago, I could have been tested then. I am lucky that nothing else has come about as a result of the HepC. I haven't any liver problems or cancer. I would have been telling a very different story if those things had come about. If I had been diagnosed earlier I could have been monitored to know if I was okay.

19. I am disgusted that my diagnosis was conveyed to me by post. In this day and age I find that to be unacceptable. Especially as I live alone.

20. I do not believe I was specifically told about the risk of infecting others at the time of my diagnosis, but the paper I received from my GP may have covered this.

Section 3. Other Infections

21. I was infected with HepC only.

Section 4. Consent

22. I was not able to consent to receiving a blood transfusion at the time of my operation as I was unconscious. I am not sure if my mother was asked for consent.

23. I am not aware of the level of consent I gave when donating blood but I know I would have been happy to have any necessary tests applied, and would have agreed to that.

Section 5. Impact

24. Physically, although I have not had any serious conditions, I haven't always been in good health. I always thought there were so many issues and all just repercussions of my accident, but now I am totally questioning this and it is more likely it is actually because of the HepC.

25. I have been in and out of hospital over the years for my shoulders, my back, and my knees, and every time I have a general anaesthetic, I get really bad infections for the next few months which require antibiotics. One surgeon also told me that I needed an operation on my nose, but once I informed him of the infections I gain post general anaesthetic he was not prepared to operate because I get infected so easily. On another occasion, when I had my wisdom teeth removed under a general anaesthetic, I developed a serious infection that turned into an abscess growing onto my jawbone. My surgeon said that in his whole career he had never seen such a serious infection. I had to immediately return to hospital for a week to have another general anaesthetic and have the abscess drained. I had a spinal operation 20 years ago, after which my surgeon told me that he was very worried about me post op as during the night I had to be monitored every 30 minutes due to a serious infection and he was very concerned on how hot I was

26. A few years ago, when I attended A&E at Frimley Park Hospital for an eye infection (blepharitis), I was asked if I had been tested for HIV, and advised that the only people who get this sort of eye infection are those with a very compromised immune system. I do not understand why I was not advised to investigate this further with my GP.

27. My HepC nurse advised on my initial review that she could tell from my viral load count of 882k that I had obviously had the virus a very long time. This made me realise that this could be the reason why I have not been feeling well since my accident in 1982. I always blamed it on the aftermath of my accident, but now I am just not sure, and this in itself is very distressing, thinking I knew

why I felt bad, and all along it could actually have been the effects of my body coping with a deadly silent killer.

28. I do not understand why doctors over the years have not done any investigations to determine the cause of my weak immune system. It has come up many times where I could not have a general anaesthetic, cannot take certain medications and my blood counts and blood pressure were always low. If I really cannot tolerate general anaesthetic, that has serious implications for my ability to get the medical care I need; that should have surely been investigated?

29. After seeing the hepC nursing team, I was started on a 12 week course of ribavirin and Zapatier. The treatment was ultimately successful in clearing the virus.

30. During my treatment, I suffered severe side effects. I was extremely weak and exhausted. People told me I looked very tired. On one occasion, about 5 weeks into my treatment, I was walking from the car park to my office and started to feel so exhausted and I found it so hard to walk up the stairs to the office. I rang my HepC nurse who checked with my consultant and advised to go straight to A&E and was told that my Hb count was very low and I had anaemia and also showing symptoms of angina. I was taken off of Ribavirin at that time. I continued having stabbing chest pains daily, but knew I had to continue with the treatment or my HepC would not be cleared.

31. The ribavirin also caused memory loss. I remember asking a question in a work meeting, hearing the answer and then realising I didn't have any idea what the question was that I had just asked. I felt like I didn't know what I was doing, and everyone else must have thought I was doing a very poor job. My eyesight went blurry, I felt jumpy, and I had throat and jaw pain. I sometimes acted aggressive or angry as a result of feeling stressed and out of control. I remember bursting into tears in the HepC nurse's office one day because the drugs were so harsh on my body and mind, I felt I just couldn't get through it.

32. While I was on the treatment, my whole life was just work, cook, and then lie on the settee. I had no energy, even at the weekends, for socialising. I just slept all day. I had to keep going to all my appointments, and make myself finish the course, but was also worried I would lose my work contract. I remember thinking, if I was on a full time permanent contract I would be off sick right now, but it's contract work so I don't get paid if I don't go in, and also as a project manager I was in charge of a team and felt I had to go in. my eyesight was also blurry and my antidepressant (for PTSD flashbacks) was not working as well as before, as I was triggered and jumpy and not my usual self I also had slight insomnia.

After treatment, some of the side effects lingered. I still have pains in my chest when walking and breathing in if the air is cold. I have had follow up appointments about my chest pain with the angina clinic, and am anxious that the treatment has damaged my heart or lungs as the pain has lingered. My joints ache so badly on waking and continue from sitting and standing and I have extreme pain in my hands and feet joints; walking is painful; my hands on time feel like robot hands moving each joint at a time, so very stiff.

33. I am single and have no support in my home. My dad and step-mum live 1.5 hours' drive away, and I didn't feel comfortable at first telling anyone else about my diagnosis. So during my treatment I still had to work, wash, shop, and cook all for myself, which was nearly impossible due to how unwell I was feeling. I felt my life was on hold as I was unable to perform my daily activities due to the treatment. The only time I ever asked for help was once, I asked a neighbour to buy me some diet coke as it was a very hot spell and I needed some relief. I felt so frustrated that I couldn't even make it to the shop to buy some drinks.

34. Even after the treatment, I have not been able to get back to my normal life as I would have hoped. I have had to cancel planned holidays as I had no energy to take them. I also had arranged for my bathroom to be refurbished and a garage roof to be refitted, and have had to postpone these too.

35. I do worry about the HepC coming back, even though I have been advised on the undetected status, as I know it's undetectable but it could still be there. I feel worried thinking about that.

36. I had gone from being a relaxed, calm person loving my work to a very stressed, sad, angry, and confused person. This has not been a pleasant journey and if I had been diagnosed many years earlier I may have coped with it better. I am very frustrated that this could have been sorted so much sooner.

37. I have not faced any obstacles in obtaining treatment. However, I did find it stressful to have to constantly advocate for myself at the GP surgery. I would often not get through on the phone or be held 15th in a queue, and then receptionists would not understand how important it was for me to have regular appointments with the same doctor so I wouldn't have to explain my history every time. It was very wearing.

My infected status has not impacted any other medical care I have received. Other than my private psychotherapy agenda was put on hold to cater for HepC and most conversations focussed on that only.

39. If I had been simply told, during any of those attempts, that I likely had a blood transfusion during my operation and should therefore get tested as this could have infected me, I could have been diagnosed much earlier.

40. I initially did not tell anyone about my diagnosis as I was so ashamed. However I did eventually tell my dad and step mum and my closest friends. I have a number of friends who all knew about the accident - a lot of them were involved in my recovery from it – and I did not want to let them know I had been infected by the treatment for my injuries and make them relive the accident. I felt really guilty about having to say this to them.

41. When I told my close friend, whose son is my godson, I was initially concerned that she would be worried that I would infect her son. I regularly help look after him due to his now single mum working shifts, but last year I couldn't help due

to undergoing treatment. During that time she contacted me less. This made me feel either that she was fearful of exposing him to me, or that she did not support me and would only contact me if she needed help. I was already disappointed to be missing out on my relationship with my godson son due to my treatment, and struggling with the side effects, so I felt abandoned at a very vulnerable time. However, we have been able to talk through it and repair our relationship; we continue to be close.

42. Because I've had so many operations arising out of my accident, I feel I am always in hospital and didn't want to put another worry on my friends by telling them about the HepC. They don't know what to do to help; they come over, but I didn't have any energy for even sitting up and talking on times It was very difficult. I had a friend come over who sat for half an hour in my garden with me, and then I said I felt so tired that I need to go to bed, so then she had to leave. Luckily, because they are such good friends, I felt bad that I was not around or accepting invites.

43. I also had to locate and contact an ex-partner of 20 years ago who I was with for 7 years and advise them of my infection, as I didn't want to feel that I may have given it to them. They are married now, and I felt so bad having to work out how to contact them and then have to step into their lives and advise them of what they needed to check. I felt so to blame, and hoped that having to speak to them did not affect their relationship at all. It was a very difficult decision to make to call them, but it was the right thing to do, or I may never have forgiven myself.

44. I feel my diagnosis has had a lot of impact on my dad and step-mum. They are 80 and 76, and felt I should be helping them, not them helping me. My dad seemed devastated at hearing of my diagnosis; he looked so upset. However, he was very supportive and kind to me.

45. In terms of the effects on my work, I was constantly worried during my treatment and afterward, as I continue to struggle with the effects, that I would

lose my outside IR35 contract. I was a working full time, 40 hours a week as an project manager and could not take any paid time off sick, so I had to keep going and pretend everything was okay. I was having to use my brain a lot and it was so hard as my brain wasn't working normally. I kept missing meetings, and felt my work slipping. I had to tell the guy I reported to about having treatment as I didn't know what was going to happen. I was afraid the medication might affect my mind, so I asked him to tell me if I acted irrationally at all so that I could make sure I was doing the best professional work. Ultimately I was able to complete the contract I was working on during treatment and did not lose any income, but it was very hard as I kept missing hours of work and had to make them up later.

46. I have had some financial losses which I would not have incurred but for my infection. I had to pay for hospital parking and petrol to travel to my many treatment appointments.

47. I also had to pay for psychotherapy. I did receive some sessions for free through EIBSS, but I still continue to attend therapy on a private basis. I had intended to seek counselling mainly to discuss the PTSD I have from my accident and family issues. However, I have found that I have been spending significant time discussing issues arising out of my infection with HepC and putting everything else on the back burner. This has gone on for a year; I feel I still have not resolved my other issues and have now been paying out of pocket to discuss my HepC.

48. I also had to pay to attend the Inquiry hearings, and had to miss work on the days I attended, so lost income from those days.

Section 6. Treatment/Care/Support

49. I do not feel I have had difficulties obtaining treatment as a result of my HepC status.

50. I applied for EIBSS financial assistance. I was also reimbursed for 12 psychotherapy sessions.

Section 7. Financial Assistance

51. I applied for and received financial assistance from EIBSS shortly after my diagnosis. I do not remember how I found out about EIBSS – it may have been from my hepatitis nurse, or I may have looked it up online.

52. I now receive monthly payments from EIBSS. The payments are not guaranteed to continue for the rest of my life, but I understand that they will continue for now and I am grateful for that.

53. I think the amount of financial assistance provided by EIBSS is not sufficient, especially when compared with other schemes. For example, the Government's response to the Covid-19 pandemic was to provide £2,500 monthly to people on furlough, this is obviously seen as what is needed to live. If that is the amount provided to people for something that was not the Government's fault, I believe there should be more assistance available for victims of a tragedy caused by the Government and NHS.

Section 8. Other Issues

54. One issue that I hope the Inquiry addresses is that there are many people who still do not know they were infected. These people may not have understand the risks involved when they were administered transfusions and therefore would not know now that they are part of an at risk group. I think there should be a way to locate and inform these people of the need to be tested even if it is not clear if they had received a transfusion.

55. I did not know about the Inquiry until last year. If I had not continually pushed for access to my medical records and answers to why I cannot donate blood I

would have never known about the infected blood scandal at all. The fact that I was rejected from donating blood twice based on my operation in 1982 shows the protocol is not intended to help people but more to push people away and not inform them they are at risk. This is unacceptable.

56. In my own experience doctors did not flag key symptoms that I was having over a period of years. Many blood tests over the years gave results that were low but this never prompted any GP for further tests. I think that protocols should change so that doctors look out for symptoms and test results that could be indicative of hepatitis, especially in people who have had transfusions, or had operations or were in hospital in those time periods and refer them for testing.

57. When I requested my records from the Royal Surrey Hospital, they said they were unable to find any information from that time **(WITN3916003).** My GP surgery also said they have no record of my transfusion **(WITN3916004).** I find it hard to believe that I had a major accident in 1982 in which my friend was killed and the Hospital has no record of it.

58. I also had to raise a complaint with my GP surgery about the way I was being treated when trying to get copies of my medical records. I was initially told by a staff member at the surgery that it would be difficult to copy my records because there were so many. I said "I know there's a lot of data, but I need this, and my doctor said it's fine". Someone from the surgery then rang me up and said "You have to come and view this data to make sure you're happy with it", so I had to sit there and read it in the middle of the waiting room. They then said, "You know there's a lot of paperwork here, we can't keep doing this, it takes months, we might have to charge you". I raised this with the practice manager because you don't have to pay for records for HepC claims, and the staff shouldn't be speaking to me like that. A copy of my records where sent on.

59. I also had trouble obtaining a letter from my GP confirming my diagnosis for the purposes of my EIBSS application. I rang the surgery and asked if they could

get the doctor to sign it, and the receptionist said there would be a charge for signing it. I explained that there shouldn't be and asked if she would just take the form to the doctor. The staff didn't seem to be aware of how to manage HepC victims.

60. Ultimately I found the process of going back and forth between the GP surgery, hospital appointments, financial assistance applications, records requests, all while holding a full time job and recovering from treatment, incredibly stressful. I think more should be done to streamline these processes so that people do not feel they are being tossed between services with no consideration for what they have experienced. I felt on my knees on many occasions.

Statement of Truth

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

Signed GRO-B

Dated 16.11.2020