

Witness Name: GRO-B

Statement No: WITN6032001

Exhibits: Nil

Dated: 27 January 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 04 January 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B (formerly GRO-B). My friends and family call me GRO-B. My date of birth is GRO-B 1946. I reside at GRO-B GRO-B Sheffield, GRO-B. I have been married twice, my second husband passed away in 2013. I have one daughter, two step-children, and six grandchildren. I am retired, having formerly been employed as a social worker with the GRO-B and later GRO-B the job from which I retired.
2. I intend to speak about my infection with Hepatitis C ("HCV") after having received two blood transfusions between April and May 1990 at the Northern General Hospital. In particular, I wish to discuss the nature of how I had learned about my infection, how my illness affected me and my family, and the treatment that I have received.

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3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I do GR
O-B wish to be anonymous as I wish for my story to be known in full.
4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism and to know my identity, whether I have chosen to remain anonymous or not.
5. I wish to acknowledge that I have retained a number of my personal diaries which relate to the period surrounding my HCV diagnosis, and my treatment. I have referred to these pages as a memory prompt surrounding dates and course of events.
6. I have given this statement without access to my medical records.
7. My sister GRO-B was present in the room during the process of drafting my witness statement.

Section 2. How Infected

8. Prior to April 1990, I had been experiencing jaundice, chest pains and abdominal pains. I believed that my health may have been exacerbated by being GRO-B divorced from my first husband. I attended the Northern General Hospital in Sheffield, to seek medical assistance. After having undergone a number of tests, I was told that I had developed gallstones, so I would need to have them removed through a surgical procedure.
9. On 23 April 1990, I was admitted to the Northern General to undergo an operation to remove my gallstones. The operation was a success, and I was taken to a ward to recover.
10. Following my operation on 23 April 1990, I experienced a deterioration in my physical health. I felt immediately ill, and I collapsed. As a result, I was given

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four units of blood on 26 April 1990, and then a further two units of blood on 3 May 1990. Though I have no medical records, I distinctly recall being told what I had been given while I was in hospital.

11. I do not believe that I was provided with any information or advice by any medical professional, surrounding the risks of being exposed to blood borne infection as a result of receiving blood transfusions.

12. I remained at the Northern General for a period of around two weeks, before I was discharged home to recover.

13. For a period of around six months afterwards, my physical health did not improve. I could not do anything as I was so lethargic and fatigued. At the time, I had asked the medics what they believed was the cause of my ill-health. I was told that it was part of my recovery process. In hindsight, I now believe that the symptoms I had experienced, were attributable to the early effects of the contaminated blood.

14. Between May 1990 and 1996, my health was up and down. I had lost a lot of weight, I was fatigued and lethargic, but I kept myself going through attending work.

15. In early 1996, I attended one of two Blood Transfusion Service (BTS) sites in Sheffield to donate blood. When I donated blood on this occasion, it was for the first time in quite a while, certainly before my operation in 1990.

16. At some point not long after my blood donation, my sister GRO-B who worked at GRO-B was asked by my old GP, Dr GRO-B something along the lines of "where is your sister GRO-B now. Can you get her to contact me?" My sister had left that GP practice when she remarried, so Dr GRO-B needed to know how to get hold of me. It transpired that the BTS had contacted my old GP, thinking I was still with them. Ultimately, I contacted Dr GRO-B who advised me to get in contact with my current GP, Dr GRO-B. I had a face-to-face consultation with Dr GRO-B. I was told that something had cropped up

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with regards to my blood donation, and that I would need to get in touch with the Blood Transfusion Service.

17. As a result, I attended the Blood Transfusion Service to see Dr GRO-B. On the first occasion, during a consultation with Dr GRO-B, I was told that the blood donation I had recently provided had been screened, and that it had shown that I may have contracted HCV and that I would need to provide a further blood sample so that they could double check and confirm my HCV diagnosis. This was a devastating shock to me, I probably reacted badly and took it out on Dr GRO-B. I walked out of the surgery but my husband who had been with me came out and persuaded me to return. I was just so anxious and upset surrounding the information that had just been disclosed. Because I had moved house and GP surgery along with it, I was seemingly pushed around before I got to the bottom of what it was about. I gave a test sample.

18. In April 1996, I attended the Blood Transfusion Service for the second occasion, and it was confirmed to me that I had tested positive for the presence of HCV.

19. When I had been first made aware, I did not know what HCV was as an infection, other than it was a disease. I also did not know where it came from. However, during my diagnosis, Dr GRO-B gave me some information that provided some understanding of HCV. I was then referred immediately to Professor McKendrick and Dr Green at the Hepatology Unit at the Royal Hallamshire Hospital, Sheffield, where I was informed all I needed to know with regards to relevant information and implications surrounding my HCV.

20. I was notified that if I fell, or had an accident, I should have something on me which indicates to others that I had HCV.

21. Around this time, I was looking after my grandchildren, so I had to be cautious that they did not come into contact with my blood. If they had a bleed, my husband would deal with it.

22. I know that there can be only one cause of my HCV, one or both of the blood transfusions that I received at the Northern General on 26 April and 03 May 1990. This belief results from a conversation I had with Dr GRO-B at the Blood Transfusion Service, when following my diagnosis, I asked him where he believed that I had contracted my infection. In response, he had asked whether I had previously had a blood transfusion, to which I had told him about the blood transfusions I received in 1990. He stated that this was the most likely cause of my HCV.

23. I was particularly upset because it was not something that had occurred naturally within me, like my gall stones for instance. Neither was it through any fault of my own such as lifestyle choices, it was something that was given to me by the NHS.

Section 3. Other Infections.

24. Other than HCV, I do not believe that I have contracted any other infection as a result of being given contaminated blood in 1990 at the Northern General.

Section 4. Consent

25. I do not believe that I have been tested or treated without my prior consent having been obtained.

26. I am sure that I would have provided consent for the blood transfusions I had received at the Northern General in 1990, if I had been asked. I do not think I would have had any real choice, I may have otherwise died. However, whether any consent I may have given would have been informed consent i.e. being told about the potential risk of a virus being present in the blood given to me. I very much doubt this would have happened, knowing what we now know about the contaminated blood scandal.

Section 5. Impact.

Mental/Physical Impact

27. Following my HCV diagnosis, I choose wherever possible to get on with my life and with the illness but in the back of my mind, I was always worried about the implications of having the infection.
28. Between the point of my HCV diagnosis in 1996 and 2005, my HCV had not caused a visible physical impact on my health. I did however attend the Royal Hallamshire regularly for check-up appointments, whereby I had undergone three liver biopsies at six-month intervals.
29. I was referred to Dr Peck at the Royal Hallamshire, where I had three liver biopsies in total. For the first two biopsies, my experience was reasonable and professionally conducted, without too much pain or discomfort. However, on the third occasion in 1998, my procedure was carried out by a young doctor under local anaesthesia. The whole experience was harrowing. The young doctor inserted the needle incorrectly, leaving me in a great deal of pain. She was unable to finish the procedure, so Dr Peck had to step in to finish it. It was extremely painful and unpleasant.
30. Afterwards, I experienced after-effects of the treatment. I was left in so much pain that it was hard to live with. It continued to cause me discomfort and pain for around one month afterwards.
31. In 2005, I began to experience a number of symptoms which I believe were attributable to my HCV. The symptoms emerged gradually over the year. I was experiencing muscle and joint pain, lower back and side pain, headaches and day and night sweats.
32. By July 2007, my symptoms had worsened. I experienced liver pain when stressed, issues with my blood pressure, dizziness and numbness in my lower arms and feet, and very low oxygen levels.

Treatment

33. When I was referred to the Royal Hallamshire by the Blood Transfusion Service in 1996 following my HCV diagnosis, they had discussed potential medication I could take to treat my infection. Treatment with Interferon was discussed, to which I was told the side effects could be debilitating. As I was healthy and working at the time, I wanted to delay starting treatment as I did not feel that I would be able to cope with the available treatment. I was also told that as I was on other medication which could affect the success of the HCV treatment. So, I did not have the treatment at that point.
34. In 2008, one of the doctors said that we ought to discuss treatment for my HCV. The doctor outlined that a fifty-two-week course of Pegylated Interferon and Ribavirin was available. I was also told about the potential side effects of this treatment. As my physical health had deteriorated, I was by then retired as was my husband, I thought it would be a good time to start my treatment.
35. In September 2008, I commenced my treatment with Pegylated Interferon and Ribavirin. I was taught to self-administer the Pegylated Interferon by one of the nurses at the Royal Hallamshire, so that I didn't need to attend the hospital weekly. At first, I did not believe that I would be able to inject myself but I soon got over that.
36. Thereafter, I self-administered Pegylated Interferon once a week, and I took Ribavirin in tablet form daily.
37. The side effects I experienced as a result of my treatment were truly awful. For the majority of that year, I was confined to my bed. I experienced nausea, lethargy, and tiredness. I had awful dreams, and a very poor appetite. My husband would wake me up to give me a drink and something to eat. I couldn't eat a proper meal. I felt that I could not function.
38. As these symptoms had started when I commenced my course of treatment, and then improved six-months after I had completed the treatment, I attribute

the deterioration in my health to that of side-effects of Pegylated Interferon and Ribavirin.

39. Alongside the physical state of my health, my treatment had an impact on my mental health. I experienced brain fog and forgetfulness, to the point that I could not remember anything I had done. I was also not able to make any decisions. To date, I struggle to recall anything from September 2008 to August 2009.

40. I was not able to go out of the house alone. I felt that I was living in a bubble. When I did go out, it was to attend the Royal Hallamshire for a check-up appointment every month throughout my treatment, where I had to be escorted by my husband. During the check-up appointments they would take blood samples to determine whether the treatment was having an effect on my HCV viral load. After six months, they had said that my viral load was improving.

41. In August 2009, I finished my course of treatment. After finishing the treatment, I was still suffering with regards to my physical state of health.

42. In March 2010, I was told that my HCV had been 'cleared.' It was not until six to seven months post-treatment that my physical health began to improve. I felt as though I was finally getting back to where I should have been had I not had HCV.

43. For a couple of years after my treatment, I attended the Royal Hallamshire for regular check-up appointments, before being given the all clear in 2010.

Impact

44. When I told my second husband about my HCV, he was very supportive. This did not have an effect on our marital relationship.

45. When I was told that I did not have HCV anymore, it was a turning point in my life. From 1996 and 2010, I believe I missed out on 14 years of 'life'. I felt that I

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- could not live it the way I had wanted, and that my life was effectively on pause as I had to be cautious of my actions, especially around my grandchildren.
46. My HCV diagnosis affected me socially. I did not go out as I did not feel like myself. Prior to 1996, I used to socialise regularly.
47. I do not believe that I have experienced any stigma attached to my HCV infection. I believe this to be attributable to the fact that I have only told a handful of people such as my family and my closest friends with whom could trust. I did not want others to know. I felt ashamed that others may automatically think it resulted from my life style choices.
48. When I had to reduce my working hours from full-time to part-time as a result of the effects my HCV, I was asked by my boss why this was. I told him confidentially that I was attending hospital for my Hepatitis but I did not want anyone else to know.
49. In 1996 I contacted a support group that was concerned with HCV and HIV to discuss my HCV diagnosis. I am afraid I cannot remember the name of the group. When discussing the potential cause of my infection, they suggested that I had contracted my HCV as a result of injecting drugs. I found this insulting and distressing that they assumed that I was an intravenous drug user. At that time most people had no idea about bad blood, it was just ignorance but I didn't expect that from a support group. I believe that they must not have been up to date with their knowledge of HCV and how it may be contracted.
50. I believe that my HCV diagnosis definitely had an effect on my career and as a result, our finances. Due to the HCV, I had to halve my working hours and go part time. I had expected to work until my planned retirement at 60 but I found that I had to give up even part time work two years early at 58 years old.
51. I had for a long time been with Westfield Contributory Health Scheme, which compensates individuals for dental fees, optical costs and hospital stays etc . I was on the lowest level of compensation available. I wanted raise my

subscriptions to enable me to get larger payments but I was told that I could not because of my HCV.

Section 6. Treatment/Care/Support

52. I do not believe that I have faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HCV. I also do not believe that my infected status has impacted on the dental care I have received. In fact, the treatment that I received from the Royal Hallamshire was fantastic.

53. I have not ever formally been offered counselling or psychological support as a result of my HCV diagnosis. However, one of my friend's was a bereavement councillor, so I had informal chats with her which did help me.

Section 7. Financial Assistance

54. Prior to providing the Infected Blood Inquiry ("IBI") with my witness statement, I had no knowledge that I could obtain financial assistance due to my HCV from schemes such as the Skipton Fund and the English Infected Blood Support Scheme ("EIBSS"). I was not informed of this by any medical professional. I have now been advised by the Inquiry investigator to contact EIBSS and to make an application.

Section 8. Other Issues

55. In 2001, I was one of a number of people who brought about an action against 'National Blood Transfusion Service & others'. Although I was the named applicant, it was my late husband that initiated the action, after he had heard about a test case in Scotland. I really had nothing to do with this case, my husband did all of the communication on my behalf. Ultimately, I was given an out of court settlement of £25,000, though only received a little over £9,000 after legal fees. I have some retained some papers relating to this case.

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56. I know that although I am not able to give blood. Even though I have cleared the HCV, there is apparently still a risk. I am now concerned that if I do not opt out, my organs may be used when I die, I do not want this to happen and so I will have to find out how to do this.

57. With regards to the Contaminated Blood Scandal, I am aware how it happened and I understand that the authorities in the UK, were aware that the blood that was being imported from USA was not safe for many years and allowed it to continue. I don't know why the blood was not tested.

58. I count myself 'lucky' that I was provided with treatment for my HCV. But for my early diagnosis and my treatment, I might not have been here today. If I had not donated blood which resulted directly with my HCV diagnosis, then it is very likely that my HCV would have attacked liver over many more years until my health deteriorated and stronger HCV symptoms had become apparent.

59. The process of providing my witness statement to the IBI has brought back a lot of painful memories.

Statement of Truth

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

Signed GRO-B_____

Dated 27-1-2022.