Witness Name: GRO-B
Statement No.: WITN1968001
Exhibits: [WITN1968002 – WITN1968011]
Dated: 30 January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

I, GRO-B and my date of birth is GRO-B will say as follows:

1. My address is known to the Inquiry.

2. I met GRO-B: H in 1976 when I was 18 and he was 23. We bought our own home in 1981, married in 1987 and had two daughters in 1988 and 1992. He was diagnosed with Hepatitis C in 1997 and died in 2000, aged 42 years.

3. I remarried in 2003 and moved from Bristol to Wells in 2015. Our two daughters still live in Bristol and are now aged 30 and 26.

Section 2. How Affected

4. My late husband, H, badly broke his leg in 1982 and it was pinned with a Kutschner nail. Over the next couple of years he had deep vein thrombosis and haematoma.

5. H was admitted to the Bristol Royal Infirmary for the haematoma on 18/03/1983. He received numerous blood transfusions. The details of the blood products given to the ward were five bags with batch numbers: 51695; 51575; 51722; 510405; and 51582 (**WITN1968002**). The ward notes of the same date confirm the administration of the fresh frozen plasma at half hourly intervals (**WITN1968003**). On 19/03/1983 the doctor's discharge summary confirms fresh frozen plasma was administered on 18/03/1983 (**WITN1968004**). There is a reference to Factor 8 also being administered in the laboratory report of 18/03/1983 (**WITN1968005**) and the later Skipton Fund application dated 06/04/2011 (**WITN1968011**, see page 6).

6. No information or advice was provided to either H or me before he received the transfusions about the risk of being exposed to infection.

7. In 1985 the Kutscher nail was removed. Unfortunately his mental health deteriorated and he began taking medication for this, along with pain relief for his leg.

8. Neither his physical nor his mental health improved and he suffered two bouts of pneumonia and an inguinal hernia. By 1996 he was taking more medications and feeling very low, e.g. depression, fatigue, lack of concentration, dry mouth and sleeping disturbances and was declared unfit for work by the Department of Health and Pensions.

9. H watched a Horizon programme which discussed Hepatitis C and recognised some of the symptoms. He asked his doctor for a blood test which came back positive. He was diagnosed with Hepatitis C on 11/02/1997.

10. The GP gave him the results over the telephone and asked that he and I attend an appointment with him to discuss the results. He outlined the risk of cross contamination and he recommended that I be tested for the virus; and that both of us be tested for HIV (luckily negative). Very little information to understand and manage the infection was given to us as far as I remember, apart from the risk of cross contamination by blood and being advised that if I was free from the virus, the children would be also so there no need to test them. No side effects of the virus were discussed. The specialist said H would be monitored but that there was no need for any treatment at that stage.

11. In terms of how the test results were communicated to us, I think that the GP was as shocked as we were. He was factual but didn't know much about the virus or treatment hence the referral to a specialist. As we did not find out that he was infected until 1997 it would have been difficult to provide any information earlier. He had not been tested until he asked to be.

12. H had been infected with Hepatitis C as a result of the blood transfusions in 1983. Correspondence between his consultant and GP on 24/02/1997 confirmed his hepatitis C was, '*almost certain to be arising as a consequence of his blood transfusions in the early 1980s since it wasn't until about 1990 that blood was screened for this particular virus*' (**WITN1968006**).

13. H went downhill quite quickly. On 29/09/1999 his specialist was content with his blood results and asked to see him again in six months. The repeat blood tests on 14/04/2000 showed changes and a

biopsy was carried out on 29/06/2000 which identified the need for Interferon and Ribavarin treatment. This commenced on 21/09/2000.

14. Given his depression, the specialist identified the need for careful monitoring of his mood due the link between the drugs and suicidal thoughts. Correspondence from the Specialist Registrar to GRO-B GP dated 23/08/2000 recommends starting treatment, but noting, '*My only concern about treating him is that he has a past history of depression and we would need to watch him closely when he starts on Interferon which certainly has some effect on mood in many patients. However, given the progression of his disease I think it reasonable to commence as long as we proceed carefully*', **WITN1968007**.

15. H first check up on 19/10/2000 did not carry out an objective assessment of his depression (see **WITN1968008** for clinic notes) and he lost his life on GRO-B 2000 after taking an overdose of his prescription medication.

16. On 30/06/ 2017, Dr Fiona Gordon, Consultant Hepatologist, confirmed in correspondence obtained for the purposes of obtaining compensation from the Skipton Fund that, '*I think it likely that* H *suffered worsening pre-existing depression due to the Interferon and Ribavarin treatment he received in 2000 for transfusion-acquired chronic hepatitis C infection, despite lack of supportive evidence in his medical records, and that this contributed to his death. This conclusion is based on my 14 years of experience as consultant hepatologist with an interest in Hepatitis C*', (**WITN1968009**).

Section 3. Other Infections

17. I do not believe that GRO-B received any infection other than Hepatitis C as a result of being given infected blood.

Section 4. Consent

18. I do not know whether H was treated or tested without his knowledge, his consent, without being given adequate or full information, or for the purposes of research.

Section 5. Impact

17. As the virus progressed, H physical and mental health deteriorated and he became more dependent on me. He felt very depressed. As I have described above, by 1996 he was taking more medications and feeling very low, suffering with depression, fatigue, lack of concentration, dry mouth and sleeping disturbances. He was declared unfit for work.

18. Everything changed. From being a very sociable person with lots of friends and activities, he became more introverted, depressed, and dependent. His mood swings were to be expected but presented difficulties and were not easily understood by people who did not understand or know the nature of his illness. We were a young family who saw our plans for the future radically changing.

19. H developed further medical complications resulting from the infection. He suffered with anxiety and depression. On 07/02/1996 he developed pneumonia, and then again on 26/06/1997. In August 1998 he suffered with heart burn and chest pain. In September 1998 he felt very lethargic and in September 1999 he suffered from tiredness and apathy. In April 2000 he complained of itching.

20. The mental and physical effects of the treatment regime were awful. H became very weak and felt dreadful. His depression worsened. His depression should have been closely monitored as the

Specialist Registrar had recommended (see above) but, unfortunately, this did not happen and he took his own life

21. As a result of his infected status, no dentist would treat H and he had to be referred to the Dental Hospital. This was stigmatising as the dentists (normally students) would not have been aware of how he contracted Hepatitis C.

22. Apart from the shock of being diagnosed with Hepatitis C, we were left feeling stigmatised as the medical profession seemed to assume that H was either an intravenous drug user or a homosexual. Consequently we didn't discuss the nature of his illness with anyone and felt marginalised.

23. H was extremely depressed and ill during his treatment. This period was an awful time for me and our two daughters. His death was not only a shock but another stigmatising event for us to endure. The coroner's report was published in the local press and this made it even more difficult to manage our grief. I had a nervous breakdown and the girls went to stay with their grandparents who lived in France for a few weeks. I returned to work after a couple of months' sick leave and was very lucky to have a supportive employer. It was a dark time for us but I remarried in December 2003 and we all rebuilt our lives.

24. It was difficult for the children to understand their father's illness and subsequent death. It affected their schooling and their emotional and psychological health.

25. As H could not work at all and was reliant on sickness benefits, our monthly income reduced substantially, which created additional stress. During his illness I was working full time and supporting him as much as possible. Our two daughters were born before his diagnosis in 1988 and 1992 and as he was not able to care for them adequately, given his physical and mental health, they went to child minders and

nursery school until they were old enough to go to school. This was very expensive and very tiring for me both physically and emotionally.

26. There was no financial support available from any of the Trusts or Funds prior to 2011.

Section 6. Treatment/Care/Support

27. Although H did not face any difficulties or obstacles in obtaining treatment with Interferon and Ribavarin, he did not receive appropriate monitoring of his mental health during this treatment.

28. As far as I am aware, H did not receive any counselling or psychological support at any time, just pills. Evidence from self-help groups in the United States in the 1980s reported that the treatment regimes were brutal and mainly unsuccessful. Many victims died while waiting for transplants. This didn't give my husband much hope for his future.

29. After H death there appeared to be some concern that I would bring a claim against the NHS. One of my husband's consultants rang me shortly after his death asking if I was happy with his treatment. At that time, I had no real insight into the depth of the 'scandal', the side-effects of the virus particularly in relation to mental health, and the impact of the treatment regime of Interferon and Ribavarin. I was also in no emotional or psychological state to consider anything other than rebuilding my life and caring for my two young daughters

30. I received bereavement counselling after his death but didn't find it helpful particularly as the counsellor's welcome was, 'are you the lady who is thinking of pursuing a claim against the NHS?' It hadn't even entered my mind. My GP prescribed anti-depressants for my depression.

Section 7. Financial Assistance

31. It was only by chance that I became aware that compensation was available. There was no formal notification. My (new) husband learned about it by an article in the newspaper.

32. I have received financial assistance from the Skipton Fund in the form of an ex-gratia payment (first payment) of £20,000 on 10/06/2011. I also received the Skipton Fund £10,000 payment to Bereaved Spouses and Partners on 23/05/2017.

33. To qualify for the first payment I needed to register with the Skipton Fund and complete an application form - this required medical opinion. That proved very difficult as H GP and specialist had retired so I had to pay for a private doctor to do this. The process took approximately three months to conclude.

34. To qualify for the Bereaved Spouses payment I had to provide appropriate documentation to prove that my late husband and I were living together at the time of death; that he was infected in England; and because the death certificate does not clearly indicate that there was a causal link with Hepatitis C, provide a letter from a registered specialist supporting the view that, on the grounds of probabilities, the infection contributed to his death. That proved very difficult given his GP and specialist had retired. I sought help from a private hepatologist but he felt that as I was paying for the consultancy it could be 'misconstrued'. I therefore went through PALS and eventually the hepatologist in charge of Hepatitis treatment at Bristol BRI gave me the appropriate letter with the required wording. This was a lengthy process starting in December 2016 and successfully ending on 18/05/2017.

35. I also applied for the Additional Payment in 2011 (originally £20,000) but this was refused on the grounds that H needed to be at stage 6 liver damage and he was only at stage 4 (there was some confusion at the time as some of the documentation issued by Skipton refers to stage 4 being consistent with cirrhosis). He was however receiving Interferon and Ribavarin treatment at the time of his death due to the rapid deterioration of the disease. It was the very treatment that worsened his depression and resulted in suicide. I wrongly assumed that after proving a causal link between death and Hepatitis C that the second payment would not be refused. There was no appeals mechanism for cases that fall outside of the bureaucratically strict rules laid down by the Department of Health, who didn't even acknowledge that depression was a factor even though studies into this were available in the 1980s.

36. More recently new payments have emerged and the payment is now set and backdated at £50,000. Victims have to show that their lives have been severely affected to qualify. Unfortunately this was not the case in 2011 and no posthumous claims are permitted.

37. I faced difficulties in applying for financial assistance, including wading through the bureaucracy of the NHS, The Skipton Fund and the Department of Health. I requested H medical records from the NHS 11 years after his death in order to claim compensation from The Skipton Fund. The Access to Medical Records stipulates that particular documentation must be presented such as the deceased passport, utility bills, or bank statements from the time of death which prove that I was the next of kin and that we were living together. After such a lapse in time none of these were available. This meant that I had to provide alternative documentation to prove that I had the right to this information which took time and caused stress. Even simple requests for Freedom of Information were turned down (I was trying to find out how many victims suffered from depression before, during and after Interferon and Ribavarin treatment and how many cases had resulted in

suicide). The Skipton Fund told me that both they and all of the charities set up to administer the Government's ex-gratia payments fall outside of the Access to Information legislation and the Department of Health say they don't hold any records on this matter.

38. As my late husband took his own life due to the worsening of depression caused by the treatment of Interferon and Ribavarin, my claims for compensation from The Skipton Fund did not fall neatly into their eligibility criteria and I felt like I had to jump through hoops to qualify and had to pay for private medical advice. Unfortunately due to the rigidity of the qualifying criteria and the lack of any appeal process to consider claims that fell outside of Department of Health policy, I did not receive the second ex-gratia payment and no compensation. Subsequent compensation schemes have not included mental health as a qualifying factor, and the only support now available for mental health is in the form of income top-up and counselling payments from EIBSS, neither of which I receive.

39. I do wonder how much the administration of these Trusts and Funds have cost. There was and still is not much help financially for the families who lost love ones prior to 2003.

Section 8. Other Issues

40. Over the years since H death, I have closely followed medical research studies relating to the connection between mental health issues and Interferon and Ribavarin treatment. These published papers are numerous and available in the public domain. I therefore attach only those referred to by Dr Gordon in her letter of 30/06/2017 (**WITN1968010**). All studies I hold would of course be available to the Inquiry on request.

41. I think the Inquiry needs to know:

- exactly when it was known that blood products were contaminated;
- exactly who knew at both NHS and UK Government levels;
- exactly when these products were removed from use and how this compares with the date of knowledge above;
- attention should be given to the mental health of infected people and of lack of help given to them and their spouses – emotionally, psychologically and financially.

42. In respect of a deliberate attempt to conceal details of what happened at the time or later, then the people responsible should be named and held accountable.

43. The Inquiry should be handed the files that Andrew Burnham holds. If he believes that they hold damning evidence of wrongdoing that would lead to prosecution then this should now be in the public domain and acted upon.

44. I hope the Inquiry will be conducted as quickly as possible. However, its thoroughness should not be sacrificed on the grounds of expedience. If we want answers to all the questions being raised, then we do need a brief overview of how the scandal developed from the 1970s and was then allowed to persist over three decades. Otherwise the feeling that irregularities were covered up will simply not go away.

45. The whole blood community should be treated equally to haemophiliacs. Both groups arc victims. If the Inquiry considers compensation payments (and I believe it should) then the over-riding criterion should be that they were infected through the administration of contaminated blood.

46. Due to my own personal experiences, I was/am interested in the number of infected people who suffered with depression before and during Interferon and Ribavarin treatment; and also the number of infected

people who committed suicide due to depression. I was/am concerned that neither the NHS nor the Department of Health seem to hold any records in relation to these questions.

47. I hope the Inquiry will focus on the mental health of infected people and the lack of emotional, psychological and financial support given to them and their families, who have not just seen the suffering and death of their loved ones but also felt stigmatised throughout.

Statement of Truth

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

Signed

GRO-B

Dated 30 January 2019