Witness Name: GRO-B
Statement No.: WITN0558001
Exhibits: Nil.
Dated: 24 July 2019

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 11 December 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1945 and my address is known to the Inquiry. I am a retired State Registered Nurse and have five children, although none of them live with me locally.

2. I can confirm that I have chosen not to have a legal representative and that I am happy to provide the Inquiry team with a written statement.

3. I intend to speak about my infection with HCV. In particular, how I was infected, the nature of my illness, how the illness affected me, the treatment received and the impact it has had on me.

Section 2. How Infected

4. I was admitted to GRO-B, Obstetric Unit, GRO-B in GRO-B 1978 in premature labour. An emergency caesarean was performed and I was transfused with two units of blood on GRO-B 1978. I was given the transfusion because of a low Hb count.

5. I believe I became infected with HCV from this transfusion. I had quite a severe reaction to the blood and was given anti-histamines to reduce reaction and the transfusion was completed.

6. It was not a regular policy to give information regarding the risks of transfusion in 1978 and HCV had not yet been identified.

7. Over the following weeks after discharge from hospital I began to experience the following symptoms:
   - left sided upper abdominal pain
   - increasing nausea
   - lethargy
   - itching
   - dark urine
   - jaundice

   Blood tests for liver function were carried out and I was told that the illness was due to a Non-A/Non-B hepatitis virus and to rest and avoid fatty foods. I seem to remember that the Blood Transfusion Service had been contacted.

8. My new born (6 weeks old) daughter was seriously ill in hospital at this time and I was very distressed as I could not visit and help care for her. My mother cared for her and my other young children for over three months.

9. I was never given any information before transfusion about the risk of being exposed to infection. During 1978 my liver function tests improved, jaundice ceased and I began to feel better.

10. Approximately ten years later, I began to have various intermittent episodes of extreme lethargy, vague gastro intestinal symptoms, almost permanent left sided abdominal pain, nausea, joint pains, very dry eyes and sometimes feeling as if I had the flu. I had an intolerance of certain foods and even having one glass of wine would result in me feeling as if I had a hangover. I constantly felt under the weather, and experienced a lack of concentration which began to impede on my ability to work.

11. These symptoms were not present all the time as I had good days and bad days but having to work made it increasingly difficult to cope. Various investigations were carried out but my symptoms were explained away as stress incurred due to my marriage breakdown, bringing up my children alone and the stress of my beginning to work again in the NHS from 1984.

12. My diagnosis was given to me by the Consultant Gastroenterologist, Dr Shears at the GRO-B Hospital in GRO-B, after a series of liver scans, biopsy and blood tests; I think in 1997/98. I was infected with HCV as a result of being given blood, this was confirmed by the Gastroenterologist. He did not have a great deal to say but I do remember being told that at least I did not have HIV. I remember being informed that HCV was an unknown condition as yet but was not as serious as HBV and that the long-term outcomes were unknown at that time; more or less a wait and see condition. I was then informed that HCV could possibly progress to liver failure or liver cancer. There were no leaflets or support groups that my Consultant knew of at that time.

13. I am not sure what else the Consultant could have said or done. I was told I would be reviewed regularly and to contact the unit if I had any further issues.

14. It was a shock to receive the diagnosis (I drove through a red light on the way home) but felt somewhat re-assured that people were living with HCV for years. I enquired as to risk of infection and queried my ability to carry on working within the NHS and was informed by the Consultant that after discussion with the Infection Control Department, I was not considered to be a risk as my employment was more counselling and supporting oncology patients and their families, advice on symptom control and teaching nurses and doctors about palliative care.

15. This was a very stressful time for me as I was endeavouring to carry out a job I really enjoyed doing but there were times when caring for patients suffering from liver cancer I would become increasingly anxious wondering if I too could end up being the patient.

Section 3. Other Infections

16. I was tested for HIV which was negative and to my knowledge I have not acquired other infections from the blood transfusion.

Section 4. Consent

17. I was informed that I needed a blood transfusion in GRO-B 1978 because of low Hb. I can confirm that I was not asked to give written consent nor did any discussion regarding possible risks take place. To my knowledge, written consent and discussion on possible risks were not policy in 1978.

18. Years later, in 1997, I was given verbal understanding of why I needed specific tests to make a diagnosis of my liver pain, nausea and other vague symptoms. Tests carried out that year were: antibody, liver function blood tests, genotype testing, examination of upper gastric trait and pancreas, liver biopsy and other ultra sound and X-rays. The possible side effects were explained to me and where appropriate I signed consent for procedures to be carried out. Being a

qualified nurse, I was well aware of possible diagnostic outcomes but never thought it would be HCV.

19. The information given at diagnosis was to verify that I had HCV but not HIV, the possible implications to me of HCV and possible treatments. Although my Consultant discussed the above, it was obvious to me that at that time there was uncertainty as to disease progression and effective treatment. I got the impression it seemed people lived a long time with HCV and no further liver deterioration was obvious, whereas others became very ill progressing to Cirrhosis or Cancer. I decided that I would be assessed regularly and proceed to treatment if needed.

20. To my knowledge I was not tested or treated for research purposes. I was informed of the testing for HCV and HIV and I consented.

Section 5. Impact

21. Initially at diagnosis I was very shocked and anxious, but also felt a sense of relief that yes, there was something wrong with me: all those years of waking up most mornings permanently run down, all those other vague symptoms and investigations for query – Rheumatoid Arthritis, Lupus – tests which always came back as non-conclusive. Being told I was depressed or questioning my alcoholic intake.

22. Mentally, I felt overwhelmed, with mixed feelings of justification for all the above and, if I am totally honest, a feeling of injustice as I had been given this condition from treatment which was deemed to help me. Being a nurse, I felt I must be more in control and positive but it was difficult, and I think I blanked it out for a while as a way of coping. I felt people would judge me and make assumptions on my lifestyle, sometimes I felt unclean.

23. I decided I would only share my diagnosis with people that mattered i.e. Health Care Professionals involved and close family. As I had been informed I was not a risk in my work, (this had been discussed by the Consultant with the hospital infection control department) I carried on working, this was a necessity; I was divorced and still financially responsible for my children through university education. I decided I could be bitter and angry or try and get on with my life as if nothing had changed, but mentally HCV was always at the back of mind.

24. I developed nodules and deformity of little fingers, although not diagnosed with Rheumatoid Arthritis, I still have these which are painful. Dry eyes are still a problem despite medication.

25. I was not prescribed treatment for HCV for a few years after diagnosis as it was decided to have a wait and see approach to the condition. Then I began to experience more symptoms and was informed by the Consultant that there were fibrotic changes in my liver. He advised that I should commence treatment as to delay could increase further liver damage.

26. Genotype blood results showed I had a high active viral load and I consented to having Interferon A and Ribavirin for over 1 year, depending on how I coped with the side effects, which my Consultant proceeded to explain the possible physical and mental effects, even though he could give me no guarantee that the treatment would be successful, I felt that I had little choice but to go agree with the treatment, and fully consented.

27. Initially, the prescribed treatment was refused by the Health Authority as it had not been approved by N.I.C.E. It was deemed that there was not enough evidence to support the expense of the treatment. I was informed of this over the phone by a senior nurse from the Gastroenterology Unit. The treatment was eventually given the go-ahead a few weeks later following discussions between my Consultant, Dr Borzey (head of the Medical Department) and the Health

Authority. No other treatment was offered, I think that was the only one available at that time. I began treatment in around April 2000 and completed it in March 2001.

Physical and mental effects

28. The mental and physical side effects of the treatment, as detailed below, were intense, and at times I felt I couldn't carry on, but I rationalised this was for my own good.

29. The physical side effects included:

    a) Shivers, Rigors, flu like symptoms particularly after each dose of Interferon;

    b) Gastro-intestinal / urinary problems;

    c) Hair thinning / falling out;

    d) Weight loss / Anorexia;

    e) Most distressing was my skin seemed to smell of ammonia;

    f) Episodes of neuralgia in my head; and

    g) Low Hb and white cell count — anaemia.

30. Mentally, at times I was feeling depressed and had feelings of panic, nightmares and feeling that everything was useless – "no light at the end of the tunnel". At times, I felt as if I was living in a bad dream. These feelings were not all the time but became more often and intense as the treatment increased. The constant worry that this might not work and what would happen then, all negative thoughts at times.

31. The side effects began to affect my concentration and memory and my ability to adequately carry out my work. It was decided I had to come off work for most of

the year. Years later after the treatment I still have episodes of painful neuralgia in my head.

32. I do not think my infected status impacted on dental check-ups as proper clinical policy by my dentist was always carried out and my status was never discussed.

33. My main concerns were with the attitudes of some Health Care Professionals when blood was being taken; some even confused HCV with HIV and the non-verbal response to seeing labels of 'high risk of infection' caused many to make judgements on my lifestyle. Discussions with a senior nurse did help improve some nurses' attitudes, but I knew some were discussing my HCV status with others not concerned with my care. I was at one point advised by a very close nursing friend that my private life was being gossiped about by others. This made me even more reluctant to share my concerns with others outside of my close family and friends.

34. I was divorced at the time of treatment and my ex-husband was not aware of my HCV diagnosis and after discussion with my GP, it was decided to not disclose to him as I had been married to him for sixteen plus years before diagnosis and he had never shown any symptoms, and to date never has.

35. The impact of diagnosis with HCV on my family initially was of great shock and worry as to if they could be infected. My daughter, who was told when I started treatment, was particularly worried as I was transfused with the blood at her delivery and expressed breast milk for her (as she was in the special baby unit) although this was only given for a few days (I was too weak to provide sufficient milk). Discussing this with the Consultant was re- assuring and she has been a blood donor.

36. HCV diagnosis impacted more on my private and social life. I began to restrict my social life as I felt I would be seen as someone to be avoided and ignorant

judgement would be made. I had a few close friends but even then, I was reluctant to disclose fully my health status until I was having treatment and to some this caused a distancing.

37. As I was divorced and my children were living / working away from home and my daughter was at university, other relationships became a real possibility but I could not pursue them at length because of my fear of having to explain my health status and their possible reaction/rejection so I made the decision that I would continue to live alone. In a way my social life diminished greatly due to side effects of illness and treatment and my anxieties and shame about people being aware I had HCV.

Stigma

38. In hindsight, after diagnosis and during treatment I had no close family living nearby but I do feel there was a serious impact on my family, particularly in my ability to give them emotional and financial support through their further education; as I was bringing up my family on my own (my husband, through his own choice, had no contact with the family and did not provide financially) I tried to carry on as normal despite feeling quite ill at times.

39. The stigma I felt, after diagnosis, when reading newspaper articles about people who had these viruses led a hedonistic lifestyle; I knew this was irrational, but it's hard to feel rational when dealing with day to day concerns.

40. What I do feel is that although my HCV status was not a reason for my divorce, the years prior to my diagnosis when I was experiencing vague health symptoms did not help my marriage.

Work-related effects

41. Many years before my diagnosis and because of constant tiredness and episodes of ill health, I reduced my work hours to 24 hours per week. I was

desperate to keep my nursing registration valid and felt that for my health and for my family, even though this was not beneficial financially, this was the best option.

42. After my husband left and I was divorced I had to increase to full time work. I had numerous occasions when I was off sick but managed to work full time until my treatment began in 2000. As described earlier, I had to come off sick for about 9 months of my treatment and a month or so after. At the end of this time I only had statutory sick pay as my NHS pay had reduced to no pay in diminishing rates. I did return to work, but over the next year struggled emotionally and mentally. I found it difficult to carry out my nursing duties of being involved in the counselling and support of cancer patients and some suffering from AIDS. A few of these patients had liver cancer due to blood products, and I began to feel I think what is called now "survivor guilt'. After discussion with my GP and Occupational Health Advisor I decided to take early retirement on a reduced pension.

Financial effects

43. Financial effects were sometimes a real stress. I could not afford to pay my mortgage after my husband left and the house was to be sold GRO-C GRO-C. Myself and the children lived in a variety of rented accommodation including a touring caravan, living with friends and rented houses, some in a poor state.

44. When I was able to afford a 100% mortgage, I discovered one of the application questions asked was had I been tested for HCV and obviously once my GP had declared to the mortgage company that I actually had the virus it became very difficult to get a decent mortgage/insurance rate.

45. Any insurance policy I took out was at a much higher premium because of my health status and it seemed I was penalised for having HCV. I did eventually get

a mortgage but it was a struggle to meet the payments and other bills, particularly as three of my children were still in higher education.

46. Although working full time it was a struggle and after taking early retirement even more so, even taking odd bank nurse jobs did not really help. I eventually sold my house to pay off existing bills and help support my children through the last years of university education. I now live in a Council bungalow I shared with my mother until her death some seven years ago.

Section 6. Treatment/Care/Support

47. Treatment obstacles were explained to me in as much as many patients had abandoned their treatment due to severe side effects. One's mental state could also begin to suffer, plus there had to be a determined commitment to continue with the treatment.

48. The main issue for me was that after being told that I needed and should have the treatment was to learn that initially it had been refused by the Health Authority.

49. My only support was seeing the Consultant regularly, he said that to his knowledge there were no support groups in GRO-B at that time, however, I contacted the Liver Trust who sent me leaflets on HCV and were very helpful. Close friends and family were supportive in their own way which was limited as I do not think they really understood what I was experiencing. I went through my treatment for the most part entirely on my own as I was always reluctant to let people know what was wrong with me and why I was having the treatment. Having a designated person I could have contacted to discuss fears and concerns would have been invaluable. I found it difficult to share my diagnosis and subsequent fears with family and friends as I felt I would be viewed differently and possibly judged.

Section 7. Financial Assistance

50. I first found out about possible financial help from my sister who heard on a radio programme about the increasing concerns of being diagnosed with HCV; this was the Skipton Fund. I contacted my Consultant who I presumed completed my application to the Skipton Fund I think in 2000/2001, although I cannot be sure of the dates.

51. For this payment I completed a detailed history of how I contracted HCV and my diagnosis and treatment. This was sent to my Consultant who I presume verified my details. I was informed that this was a one-off tax-free payment.

52. As far as I can remember it was 2004/05 that I was awarded £20,000 from the fund and I used this money to help with ongoing bills and to help finance my youngest daughter at University.

53. I had no further contact with the Skipton Fund until about three years ago when I was contacted by them and awarded a monthly payment which was to stop when I died. This has now been taken over by Velindre N.H.S. Trust. I did not need to make a further application for this payment.

54. I have no real observations with regards to the Skipton Fund. I was amazed that they managed to find my address as after that initial one-off payment I had moved house a number of times due to financial problems. At my age now, 73 years old, the payment was gratefully received.

Section 8. Other Issues

55. My statement may possibly be seen as of no consequence compared to the suffering of others, but whilst I have found it cathartic to tell my story I can still remember what was a dreadful physical, emotional, social and financial time in

my life. Even now I am penalised, through no fault of my own, especially when applying for home / travel / life insurances.

56. I see this Inquiry as setting the record straight and the outcome being an acknowledgement of the devastating effect of HCV, HIV and other conditions contracted from a procedure given to save life, and the responsibility for this tragedy is identified.

57. I have no medical records or documents I can provide.

Statement of Truth

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

Signed GRO-B

Dated 25th July 2019