Witness Name: GRO-B
Statement No.: WITN2853001
Exhibits: 0
Dated: 13 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows: -

Section 1. Introduction

1. My date of birth is GRO-B. I am married with two grown up children. This is a statement of my experience of infection with Hepatitis C ('HCV') following a blood transfusion, my treatment at Stepping Hill Hospital between 1986-1992 and at Manchester Royal Infirmary between 1993-2005 and the impact of HCV and treatment for HCV on myself and my family.

Section 2. How Infected

2. I was infected on GRO-B 1986 at Stepping Hill Hospital, Stockport, from a transfusion I received on the day of my eldest son's birth. It was a difficult forceps delivery and the tear was not properly repaired. Shortly after returning to the maternity ward from the delivery room I lost a lot of blood and had to have an emergency operation under general anaesthetic to repair a 3rd degree tear. Following the operation, I was given a blood transfusion. I think I

received three units of blood. Approximately three weeks later, when I was back at home with my baby, I became ill with acute hepatitis.

3. As a result of the hepatitis infection I attended Stepping Hill Hospital Chest Clinic from 1986 onwards. My liver function tests were abnormal and it was clear my body had not cleared the hepatitis infection and it had become chronic. A liver biopsy was carried out in 1987, 12 months after I was infected. A sample of my liver was taken so it could be examined. I was told I had 'non-A, non-B' hepatitis.

4. I did not receive any information or advice about the risks of being exposed to infection through infected blood. It was an emergency and I was losing consciousness at the point when I had to sign the consent form. I remember it being explained that I had to go to theatre to have the stitches re-done and they would use general anaesthetic. I don't remember the blood transfusion being mentioned or any risk of infection being explained.

5. I was infected with HCV as a result of being given blood.

6. I found out I had been infected with HCV towards the end of 1991. This information was given to me by a doctor at an outpatient's appointment at Stepping Hill Hospital Chest Clinic where I had attended since I had the acute hepatitis in September 1986. Prior to that I had been advised I had a 'non-A, non-B' hepatitis infection. At the appointment the doctor told me my blood had been tested for HCV, a newly discovered strain of hepatitis, and it was positive.

7. I was not given adequate information to help me understand and manage the infection at that time. I asked what I could do to keep myself healthy and prevent cirrhosis or cancer developing and was told there was nothing I could do, there was no treatment available and there was a risk of becoming seriously ill from liver cirrhosis or cancer after 20-30 years. I don't remember being given any other information.

8. In terms of how the results of the test for HCV were communicated to me, I don't remember if I was forewarned about this test being done. I do remember I attended the appointment alone and wasn't expecting this news. I left the appointment feeling shocked and confused.

9. I don't remember being given information about the risks of others being infected at the time I found out. Later I sought out this information and several years later my husband and youngest son were tested and both tested negative for the virus.

Section 3. Other Infections

10. I do not believe I have received any infection other than HCV. A test for Hepatitis B was done when I had the acute hepatitis and came back negative. I don't remember ever being tested for HIV, although the possibility of being infected with HIV was something I worried about.

Section 4. Consent

11. I do not believe I have ever been treated or tested without my knowledge or consent, or for the purposes of research.

Section 5. Impact

12. The mental effects of the infection were as follows. The illness from the acute hepatitis and resulting tiredness and depression overshadowed my first weeks and months as a mum. I was a young person of 28 when I received the contaminated blood and I am now 60 years old. For much of that 32 years I have lived with fear and uncertainty about the future, not knowing if, and when, I would develop a fatal liver disease. I have had periods of low energy levels, depression and anxiety.

13. In the 1990s I felt a lot of anger and frustration. I sought out newspaper reports about hepatitis and information on treatments. I wrote to MPs and was in contact with the British Liver Trust and the Haemophilia Society. I felt frustrated there appeared to be no way to right the wrong I knew had been done to me. I often felt consumed by this anger and alone with the burden and stigma of the disease, which I kept a secret from most people.

14. I felt guilty as for several years I didn't know if I had passed hepatitis on to my youngest son who was born in 1990, or to my husband through sexual transmission.

15. My experience of being infected while in a hospital made me suspicious of the medical profession. I was particularly anxious when I attended outpatients or was admitted to hospital.

16. The mental effects eased for a time after I had successful treatment in 2003 and an ex-gratia payment in 2004 and I was able to move forward with my life. However, a series of family bereavements and sudden critical illness of a family member during the years 2002-2009 triggered in me a severe health-related anxiety disorder with worrying physical symptoms. I felt vulnerable and unsafe and thought I could suddenly get ill. I paid privately to attend therapy; three months counselling in 2010 and four months of weekly CBT sessions in 2011. This was the first time I spoke to a psychologist about the mental effects of being given contaminated blood. I gained some understanding into its impact and why I felt as I did and learnt practical techniques to manage my anxieties. My mental health has improved since this time, although anxiety has increased recently due to the forthcoming inquiry and the need to re-live events in order to give evidence.

17. The physical effects of the virus have been very many. Initially, for a few weeks I had acute hepatitis with jaundice, dark urine, sickness, loss of appetite and stomach pain. I was unable to eat and had little energy to look after my baby son. In the years that followed I had excessive tiredness, severe migraine and muscle aches. Following my second round of treatment which I

was told cleared the virus in 2003 my health improved. However, I still have periods of low energy, and inability to concentrate, particularly following moderate exercise. I enjoy walking and yoga, but I must plan to do less the next day when I know I will be excessively tired. The 'brain fog' that goes with this tired feeling gets me down sometimes and has an impact on my productivity if I'm working or needing to concentrate. I sometimes get a cramping pain in my liver and I'm worried about the long-term health impact given I had the virus for 17 years before I cleared it, and it is now over 30 years since I was infected. I haven't had any hospital follow-up since 2005. From time to time I have requested and received liver functions blood tests (ALT/AST) at my GP surgery, which have had variable results. I plan to request a HCV PCR test from my GP as I am concerned the disease has returned.

18. As for further complications or conditions which have resulted from the infection, I developed chronic psoriasis during treatment (described below). I also developed a suspicious lump in my mouth in 2004, which was removed at Stepping Hill Hospital in December of that year. It was suspected oral cancer but the biopsy results were inconclusive and it did not recur after it was removed. I attended outpatients for follow-up for five years. More recently I have had problems with gum disease. I do not know for certain if these conditions are linked to HCV but I have seen some information online that mentions these as potential long-term effects of the infection.

19. I was advised when I was referred to Manchester Royal Infirmary Liver Clinic in 1993 that Stepping Hill Hospital had lost the results from my first liver biopsy from 1987. The Manchester Royal Infirmary was concerned about this because it meant there was no baseline information on the state of my liver to compare with my subsequent biopsy results.

20. I had two courses of treatment for HCV. The first was a six month course of Alpha Interferon by self-injection in 1993-1994. I did not clear the virus but

there were improvements in my liver biopsies. The second was three to four months of treatment from January to April 2002 on combination therapy Alpha Interferon (by injection) with Ribavirin. It was planned as a six month course of treatment but was cut short due to side-effects (see below).

21. I did not face any difficulties in accessing these two courses of treatment. Manchester Royal Infirmary encouraged me to undertake both rounds and contacted Stockport Health Authority to pay for it. I do not know whether there are treatments which ought to have been made available to me as, so far as I am aware, these were the only treatments available at the time.

22. The mental and physical effects of the treatments were as follows. I suffered a severe skin reaction from combination therapy from January to April 2002. After three weeks of starting therapy an itchy rash appeared, which steadily worsened. From 6th April I was unable to work. I had to withdraw from treatment on 24th April due to the severity of the skin condition. I was referred to dermatology at Manchester Royal Infirmary at the beginning of May and diagnosed with severe whole-body infected psoriasis, which was treated with steroid creams. The reaction was so severe I was asked on the day of my dermatology appointment to allow photographs to be taken, which I was told may be used in medical training or research publications. For the first few weeks I attended a daily care clinic at Stepping Hill to have my dressings changed. After several weeks my skin started to improve. After six weeks I was able to return to work. However, the psoriasis has never completely left me: it's chronic but not severe. I have emollients on prescription which I treat my arms and legs with twice a day. My skin is thin and bruises easily, particularly on my hands, arms and legs where the skin reaction was most severe.

23. The infection impacted on my life greatly. I was a new mum of 28 when I was diagnosed and I worried I wouldn't be around for my children if I became seriously ill or died. It was difficult to balance family life against in-patient and

out-patient appointments. Waiting times at the Liver Clinic were long and attending out-patients often took half a day. Hospital procedures such as biopsies and treatment were invasive, painful and stressful involving time away from my husband and children.

24. Often my energy levels were low and there were periods when I was unwell. I decided soon after my diagnosis to stop drinking alcohol because I felt it would help my liver long-term and I tended to avoid social occasions with alcohol where I would have to explain why I didn't drink.

25. The stigma associated with HCV led to me feeling ashamed and not able to be open with friends and colleagues. I feared stigma and told few people of my illness. When I have told people, they have generally been understanding and I had few problems getting services, apart from some issues getting travel insurance which were sorted out by finding another provider.

26. I worked part-time from 1988 to 2001 and full time from 2001 until 2014 as a Charity Manager (apart from the six weeks when I was off sick during treatment). I had a three month break from employment from March to June 2014 following voluntary redundancy. I took up a new full-time job in June 2014. The work was demanding and I became increasingly exhausted. I resigned from this job in March 2018 due to its impact on my health and wellbeing. Since then I have worked in a temporary part-time role from home. The temporary role ended in November 2018 and I am currently unemployed and seeking part-time work which won't impact as much on my health and wellbeing.

27. The financial impact of the infection for me has included needing to resign from a full-time well-paid job in March 2018. As a result I currently don't have any earnings. It is five years until I can get a state pension. I do not know to what extent the tiredness that caused me to give up my full time job was caused by the hepatitis.

28. The impact on those close to me is as follows. My husband worries about my health. He has been with me through some difficult times, supporting me while I have struggled to come to terms with the virus and seeing me ill during treatment. At times this has impacted on his own wellbeing. My children were young during these events and, although they knew about my illness, I don't think they were negatively impacted.

Section 6. Treatment/Care/Support

29. I haven't faced any difficulties in obtaining treatment or care. However, I did face a difficulty in securing an adequate and accurate HCV diagnostic test, as follows. After my treatment was cut short in April 2002, a blood test for HCV by PCR (polymerase chain reaction) in August 2002 revealed the HCV virus was still present. I requested a further appointment at which myself and my husband asked if there was anything else that could be done. We were advised there was a more sensitive diagnostic test that could be used, but Manchester Royal Infirmary hadn't used it because it was expensive. When we offered to pay privately for the more sensitive test, the hospital agreed to fund it. When the new test was done, it showed a negative result, i.e. I had cleared the HCV virus, which was undetectable in my blood. This response was sustained and a subsequent test in 2004 was also negative. This was a difficult and confusing time, to first be told I still had the virus in my blood, and then that I had cleared it. Even when I got the negative result, I wasn't sure if I could trust the results.

30. Counselling or psychological support has never been made available to me in consequence of being infected.

Section 7. Financial Assistance

31. I saw some publicity about financial compensation for those infected with HCV and in January 2004 I contacted a solicitor I was in touch with who sent me details of the Skipton Fund. Then I contacted the Department of Health (DoH) to apply. I was paid a single payment of £20,000 on 19th January 2005.

32. In terms of the process of applying for financial assistance, I wrote to the DoH in January 2004. On 18th June I received a letter from the DoH with details of how to apply. A registration form was enclosed. I returned this to the Skipton Fund and received an application pack. On 4th August I sent a letter to my consultant at Manchester Royal Infirmary, Dr Warnes, asking him to complete the clinician form and send it to the Skipton Fund. I received my payment in January 2005.

33. I didn't face any obstacles in applying for financial assistance but I had to be proactive in applying and it took several months after the application to receive my payment. In total the whole process took a year. Until very recently I was unaware of any other trusts or funds or different forms of financial assistance. I was also unaware that Stage 2 payments had been increased from £25,000 to £50,000 and I was unaware that anyone was receiving annual payments. I haven't had any correspondence or communication with the Skipton Fund since my initial payment was received in 2005. I was pragmatic in accepting the one-off payment of £20,000 thinking it unlikely that more financial assistance would be forthcoming. I am concerned that the Skipton Fund has failed to contact me in relation to changes in the financial assistance regime or to transfer my details over to the EIBSS.

Section 8. Other Issues

34. I think the terms of reference set by the Inquiry are reasonable. The Inquiry needs to uncover why infected blood was being used and who knew about it,

as well as looking at the impact. I hope that those infected and affected will feel their stories have been heard and have access to equal and consistent medical and financial assistance in the future.

Statement of Truth

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

Signed

GRO-B ......

Dated 13 March 2019