

ANONYMOUS

Witness Name: **GRO-B**

GRO-B

Statement No.: WITN3478001

Exhibits: WITN3478002-005

Dated: 6th August 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 the 27th June 2019.

I, **GRO-B**, will say as follows: -

Section 1. Introduction

1. My name is **GRO-B**. My date of birth is the **GRO-B** **GRO-B** 1953. My address is known to the Inquiry. I am living in **GRO-B** **GRO-B** and I have lived here since 2007. **GRO-B** **GRO-B** I am a retired **GRO-B**

which I did from 1978 until I was forced to take early retirement due to my declining health, in 2003. I intend to speak about my infection with hepatitis C, in particular, the nature of my illness, how the illness affected me, the treatment I have received and the impact it has had on my life. I wish to be anonymous for this statement.

Section 2. How Infected

2. I was born in **GRO-B** and came to the UK in 1954 where I lived in Glasgow. I was then in and out of care until I was nine years old. My mother and I in 1962 then moved to London and **GRO-B**. **GRO-B** I moved up to Edinburgh around 1964 **GRO-B**. **GRO-B** I went back down to London in 1971/1972 where I was registered with several GPs including **GRO-B**. **GRO-B** **GRO-B** I remained in London until 2007. I have been treated at Kings College Hospital in London, East Dulwich Hospital in London (which is no longer in existence) and a hospital in Chelsea, London.
3. I realised when I was registered with **GRO-B** surgery and under the care of Kings College Hospital that there were two different versions of my name being used which created confusion with my medical records. This was mentioned to me by a receptionist at Kings College Hospital where it came out that **GRO-B** had been dropped from my name, which I consider to be liberal racism.
4. I had a miscarriage when I was about nineteen years old and was admitted to St Stephens in Fulham. I was very young and I did not even know I was pregnant, I didn't even understand how I would get pregnant. I also had a termination in 1984 at East Dulwich Hospital. These are two events that have occurred in my life which I believe may have resulted in my receiving a blood transfusion. There was also a possible third event, when I was admitted to East Dulwich Hospital where I had a foot operation in 1986. I remember waking up halfway through the operation as they had not given me enough anaesthetic which was horrific.
5. I remember I had a bag of blood attached to me through an IV when I had my miscarriage at St Stephens Hospital in the 1970s and another when I had a dilation and curettage (DNC) at King's College Hospital in London

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because I had bleeding problems in 1991. Latterly I was diagnosed with fibromyalgia in 2001, which has similar symptoms to hepatitis C. I was also diagnosed with paranoid psychosis in 2005 when I was living in London. I dispute this diagnosis. I was diagnosed with Asperger's syndrome in 2001.

6. I cannot remember details of the transfusion, I just believe at some point in my life I have had a transfusion. I remember when I had the miscarriage I had a bag of blood, so this was in 1974/1975. I was in hospital for quite a while after then, for about three or four weeks but I am unsure on the exact dates. What I can recall is that I was bleeding and I went to a GP but the bleeding got worse and worse, so I went to accident and emergency and then I passed out. I was out for the count for a few days and when I woke up I was in a ward, but no one explained anything. I cannot recall any conversations with the doctors. No medical professional ever told me anything in those days and I do not have any idea how many units of blood I received. I exhibit two entries from my medical records that refers to this miscarriage, which I understand often would require a blood transfusion for significant blood loss, which there was. I exhibit this under **WITN3478002**.
7. After this I remember developing severe depression in the 1980s and then I was diagnosed with fibromyalgia in 2001/2002. I remember in the year 2003 I went to **GRO-B** **GRO-B** because I had turned yellow. My GP didn't take any blood at this point, she just completely dismissed me. I was tired, exhausted, depressed and yellow. The yellowing of my skin faded over time, so nothing further happened at this point.
8. I moved up to Scotland in 2007 where I registered with the GP in **GRO-B** **GRO-B**. I can't remember the details around my diagnosis of hepatitis C, I think they took a blood test. I was diagnosed in around 2012. I exhibit the laboratory result confirming this under **WITN3478003**. I had to get treatment for it in 2015 and I still have to go in every six months to be checked because I have developed cirrhosis. I can't remember what information was provided to me at the point I received the test results. What I do recall is that I had a letter to go see a hepatitis C nurse at Edinburgh Royal Infirmary called **GRO-D**

GRO-D

She kept going on about drugs and I kept saying to her, I don't do drugs.

9. I asked the nurse how had I been infected, but she said she didn't know. She didn't say anything to me about a blood transfusion she just kept referring to me using drugs. I kept saying no, I am not a drug user and I did mention that I had received a blood transfusion, but she didn't say anything further to me after this. The information was not adequate because nothing was explained to me. It wasn't until I looked on the internet that I realised the full implications of having hepatitis C.
10. Information about hepatitis C should have been provided a lot earlier. For starters I should have been diagnosed earlier, it was a missed opportunity when I raised with **GRO-B** that I was yellow. The hospital should have spoken to me earlier as well and explained that I had received blood and what the implications were. I think in those days hospitals thought that patients didn't have the right to know any information and that they were the 'Gods'. I exhibit a letter from my doctor from 2001 under **WITN3478004** that indicates that I had raised LFT results and that they warranted further investigation. There is no evidence in my records that these further investigations took place.
11. When I was diagnosed, I was relieved to know that this was the probable cause of all my symptoms. It was explained to me that it was quite a serious condition and I was already at the stage of having developed chronic cirrhosis of the liver.

Section 3. Other Infections

12. Until my medical records were recovered by my solicitors, I was under the belief that I had only been infected with hepatitis C, however the records say that I have had a past infection of hepatitis B which has never been mentioned to me. I exhibit a letter dated the 18th June 2012 under **WITN3478005**.

Section 4. Consent

14. I wouldn't know if I had been treated or tested without giving my knowledge or consent, no one has told me. I have never received full information for hepatitis C from the doctors or the risks associated with receiving the blood when I had the transfusion.
15. I was part of research when they were giving me medication for treating the hepatitis C but I gave my consent.

Section 5. Impact

16. Initially it was a relief when I was diagnosed because I had an explanation for all the symptoms I had been experiencing. I was depressed but that was due to **GRO-B**. **GRO-B**. I now have chronic cirrhosis which is a direct result of the hepatitis C infection, my liver does have evidence of being scarred. I have fibromyalgia and chronic fatigue as well. There have been times where the symptoms of this have been so severe I haven't been able to get out of bed.
17. In the early 1990s, when I was in my thirties I went through early menopause. I never understood why this had occurred which robbed me of the chance of having my own family until after my hepatitis C diagnosis. Now I know through research that there is a link between the two.
18. I took treatment shortly after my diagnosis. I cannot recall the names of the drugs. I did the treatment for a year. I cannot remember too much detail about this. I felt unwell on the treatment, but I felt unwell anyway, so it made no difference, the treatment was ok, it wasn't invasive. They offered injections at first, but I could not inject myself. The treatment I ended up taking was in pill form. I cannot remember any symptoms from the treatment now. I have been declared clear of hepatitis C since 2015, but I have been left with cirrhosis of the liver. I have to go to hospital at the Edinburgh Royal Infirmary every six months now for check-ups.

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My liver at my appointment in January 2019 said that I was showing that I had non-chronic liver disease which is now kept under review.

19. I had to tell the dentist I was infected, but there was no change in my care. I have lost a lot of teeth over time but I don't know if that was related having gum disease in 2000 when I was living in London. I have lost a lot of hair as a result of hepatitis C, which has been very distressing. Around 1995, what I now know is due to my compromised immune system, because of hepatitis C, I diagnosed with osteoporosis which has been debilitating. All the way through the 1990s I was exhausted all the time. I literally struggled to get out of bed I felt so bad.
20. I was in the GRO-B from the 1978 until 2003 as a GRO-B. I started taking a significant amount of time off work in the 1990s when I wasn't able to get out of bed and my health began to decline. My ability to concentrate became a problem and it got to the point where they were going to discipline me. I had no choice but to retire as otherwise I believe I would have been fired. I was so sick at that time I could not even fight them. The last two years of my working life, I went part-time because I could not cope with full-time hours anymore. I have only received two thirds of my retirement pension instead of the full amount as I was two years short of being eligible for the full retirement pension. I am angry about this and feel it was due to pressure that was placed on me by my supervisor to leave. When I reflect back on the consequences of having to retire early, it becomes extremely upsetting. I was earning £30,000 per year at the point I had to leave in 2003. It has plunged me into the benefits system and prevented me from developing my career. It is an incredible loss of earnings, and an incredible loss to society that I was forced to stop working because of hepatitis C.
21. My friends would come and visit me when I was really tired so there hasn't been a negative impact from this, I've not experienced any stigma from having the infection.

Section 6. Treatment/Care/Support

22. I am forced to take the home-helper fee out of my Mum's benefit money now for support, as I need assistance for the two of us. My PIP has been cut to low rate from middle rate care even on appeal and that is with my diagnosis of cirrhosis. This has caused significant trouble because **GRO-B**
- GRO-B**
- GRO-B** Because of my health, I also need assistance. No one told me that I could also access a lift from the voluntary service at Edinburgh Royal Infirmary either, so when I went for my six monthly appointments initially, I was paying for a taxi at £75 a time for each appointment. This meant that sometimes I could not afford to go to the hospital. I found out this was an option purely by accident, no one gave me the information.

Section 7. Financial Assistance

23. I have no awareness of the financial assistance schemes and what is involved with them. I have never heard of SIBSS or EIBSS. I do receive PIP but this has been reduced to a low rate as I describe above.

Section 8. Other Issues

24. I have no other matters to bring to the Inquiry's attention.

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Statement of Truth

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

Signed

GRO-B

Dated

May 27, 2020