

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN4071001

Dated: 3 August 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 13 March 2020. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

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

1.Introduction

1. My name is **GRO-B** My date of birth is **GRO-B**
GRO-B and my address is known to the Inquiry. At the time of infection my name was **GRO-B**
2. I am separated from my wife of **GRO-B** years. I have **GRO-B** grown up children and **GRO-B** grandchildren. **GRO-B** of my children **GRO-B** **GRO-B** and the **GRO-B** in **GRO-B** My mother and sister **GRO-B** to me.
3. I was infected with hepatitis C in **GRO-B** following receipt of contaminated blood products during a blood transfusion.

2.How Infected

1. To my knowledge I was infected with hepatitis C after receiving an emergency blood transfusion following a motorbike crash in August [GRO-B]. As a result of the crash I sustained severe injuries and received the transfusion at [GRO-B] [GRO-B] in [GRO-B]. Unfortunately, there is no record of the accident or subsequent transfusion in my records but there are references to the transfusion throughout my records.
2. When I was around the age of [GRO-B] I did have a push bike accident where I also received 1 or 2 pints of blood but this transfusion took place at [GRO-B] [GRO-B] Hospital in England. As I am a beneficiary of [GRO-B] and not [GRO-B] I assume that the hepatitis C must have come from the transfusion in Wales and not the transfusion in England.
3. I think I found out that I was infected with hepatitis C in [GRO-B]. My notes say that hepatitis C was detected in [GRO-B] and this was confirmed following a blood test in March [GRO-B]. Around this time I had been to give blood as I had wanted to do something to help others because the blood that I had received during my transfusion had saved my life. Not long after donating blood I received a letter from the Blood Transfusion Service (BTS) which said that they had found something in my blood, I think they may have mentioned hepatitis C, and to make an appointment with my GP.
4. I attended an appointment with my GP around one to two weeks after receiving the letter from BTS. I instigated the booking of the appointment. I don't recall that the GP was aware of the letter I had received prior to me attending the appointment and requesting a hepatitis C test. However, my records include a letter from the Blood Transfusion Service to my GP dated August [GRO-B] to advise them that I had received blood prior to 1991 and was at risk of having hepatitis C.
5. I was provided with very little information by either BTS or my GP in regard to hepatitis C and there was no discussion in regards to any potential health

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issues I may experience. I got in touch with The Liver Trust and they provided me with more beneficial information. The Liver Trust have been a great help to me over the years. In GRO-B it was a lot more difficult to get information on the internet about hepatitis C compared to today.

6. The communication I received about hepatitis C and how I came to be infected was woefully poor. There should have been support in place from the start so I could come to terms with what the infection was and how important it might be to my life and also on how to keep others, especially my family, safe. I was left to stand on my own with no support to come to terms and deal with the hepatitis C infection.

3.Other infections

1. As far as I am aware, I have received no other infections. However, I wouldn't rule out other infections that I haven't been told about after what has happened to me.

4.Consent

1. In regard to the transfusion itself I received this in an emergency situation and I wasn't conscious at the time so I was unable to provide consent.
2. I am pretty sure that I have been tested on without my consent as the doctors knew what was in the blood when they gave everyone the infected blood.

5.Impact

1. Initially when I was told of the hepatitis C infection in GRO-B I was fearful and anxious as I didn't know anything about hepatitis C or how I had got it. During the first few years of being told of the hepatitis C infection physically I felt nothing different and life carried on as normal.

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2. Around [GRO-B] I was offered treatment for the hepatitis C in the form of Interferon and Ribavirin and the treatment commenced in June [GRO-B]. Initially the treatment was due to last for six months, but I ended up enduring the treatment for a full twelve months. The starting of this treatment was the starting point of me feeling worse both physically and mentally.
3. Over the intervening years I have experienced depression on and off which has increased over the years and my body has become hyper-sensitive (both my muscles and my skin). I have experienced several health issues including pancreatitis and a brain haemorrhage for which I had surgery for both in [GRO-B] and [GRO-B] (my own research has indicated that the percentage chance of a haemorrhage increases as a result of the hepatitis C treatment).
4. In relation to the brain haemorrhage, my first operation in July [GRO-B] was to insert a coil and this was done through keyhole surgery so the recovery time was relatively short. I then required a further procedure in March [GRO-B] to insert a clip but this was a much more invasive procedure. When I went into hospital for this second procedure the Consultant was not aware that I had hepatitis C and he delayed the procedure for six months. I was told that this was due to the cost of the instruments required to carry out the procedure. This six month delay was through no fault of my own but could have been severely detrimental to my health. I had repeatedly told the doctors of the hepatitis C and this would have been in my medical notes so I am at a loss as to how the Consultant was unaware until the day of my operation.
5. At the time of the treatment I was working as a full time [GRO-B]. I recognise that there were stresses and strains to working in such a field and I do factor that into my current situation. However, my underlying health was affected by the hepatitis C that lay undiagnosed for years. My depression, anxiety and physical wellbeing have all been affected by the hepatitis C.
6. I have no idea if I have actually cleared the hepatitis C virus as I don't recall ever being told this information following the completion of the treatment in [GRO-B]. The impression that I get is that I have cleared the virus but I know that

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I still carry the antibody and this will always be in my body. My notes say that in August **GRO-B** following treatment that hepatitis C was not detected. I do receive yearly liver and kidney tests to check my LFT's but I think this is more to do with the fact that I have an issue with my blood pressure rather than that I had hepatitis C. I don't believe that I am being specifically monitored in relation to the hepatitis C.

7. I believe that I was part of a test programme with the Interferon and Ribavirin and that is why I was offered the treatment and didn't have to request or fight for it.
8. I don't know if there were any other treatments that should have been made available to me. As far as I was aware the treatment that I had was all that was available at the time. I wasn't provided with any information regarding treatments so I have nothing to compare what I received with what was available at the time.
9. I have moved about a bit over the years and it still surprises me how little doctors know about hepatitis C. I constantly have to explain my history to any new doctors that I see. This should all be in my medical records, so it always surprises me how often I have to explain my medical history.
10. I haven't experienced any stigma in relation to hepatitis C but that is because I have always been very careful with who I have told. I have declared the infection on work applications when requested but only my close family are aware that I was infected.
11. I have definitely experienced work-related effects as a result of the hepatitis C. I am currently not working and was signed off sick sometime between **GRO-B** and **GRO-B**. I can work but I just can't guarantee that I can get up for work on time and after two or three days of work in a row I'm exhausted. I physically don't have the energy to be able to work despite the desire to.

12. My GRO-B children weren't impacted physically as there was no transference of hepatitis C to either child as I was extremely careful around the home. Emotionally however it has been extremely hard for them. We all get ill but my illness could and should have been avoided. It has been an emotional theft for me and my children.

13. This Inquiry has helped me come to terms with the hepatitis C and the way in which I was infected. Whilst it is hard to hear other people's stories it has helped to put a few things into perspective and answer a lot of questions. I now know that I am not alone. When I was first told I had hepatitis C I had no idea that there was a whole community of people who had been infected via contaminated blood.

6. Treatment/Care Support

1. As already mentioned in my statement treatment was offered to me in GRO-B but I was provided with such a lack of information about the treatment itself before starting it, that the side effects had a huge impact upon me.
2. Only in the last couple of months has there been a counselling service that has been made available through GRO-B. I only became aware of the fact that I could speak to a person directly when I attended the Inquiry Engagement Meeting in GRO-B on 17th February GRO-B. I was aware that there was an online service but I don't want to talk to a computer. I haven't accessed this service as of yet as part of the depression I suffer is having the motivation to start the process.

7. Financial Assistance

1. Through my conversations with The Liver Trust I was advised about the Skipton Fund and received £20,000 as a lump sum from Skipton (I can't recall the year I received this) and I had to sign a document that said I would take no further action following receipt of this payment. My doctor at the time confirmed that I had received a blood transfusion which resulted in my

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hepatitis C infection. As far as I am aware Skipton did not request any further evidence.

2. Around three years ago I was looking on-line and found out by accident about the ongoing payments that I would be entitled to from the Skipton Fund. I initially received £3,500 per year which increased to £4,300 per year. Last year I disclosed the impact hepatitis C has had on my mental health and I now receive £15,000 per year. I had to contact Skipton directly for the ongoing payments as they never made contact with me to inform me of the additional payments I may be entitled to despite already having my details on file from receiving the original lump sum.
3. Parity is a major area of concern. When we were infected the National Health Service was one organisation and there was no devolution of the health service. All of those infected regardless of the area of the UK in which they were infected should be treated equally.

8. Other Issues

1. I have been unable to obtain a mortgage or life and holiday insurance and this has had a negative impact upon me and my family. There is just no way around the cost of insurance when you have to declare hepatitis C on the application despite contracting it through no fault of my own.
2. Again, I would like to re-iterate how I feel about the parity issue regarding payments. We have all had to live with the consequences of infection regardless of where we were infected so we should all be treated as one.
3. Sometime around GRO-B I received a letter from the NHS instructing me not to give blood due to the hepatitis C. This letter also stated that there was a possibility that I may also have been infected with Creutzfeldt-Jakob disease (vCJD). There was no offer of any further information about this!

Statement of Truth

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

Signed:

GRO-B

Dated 3.8.2020