

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2566001

Dated: 12th March 2019

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 12th December 2018. 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 and my address is known to the Inquiry.

2. I am married to GRO-B and have GRO-B sons who are GRO-B and GRO-B years old. I live with my wife and GRO-B of my sons. I retired from my job, as a GRO-B with the GRO-B through ill health about GRO-B years ago.

3. I intend to speak about my infection with hepatitis C (HCV) which I contracted from infected blood products sometime between the late GRO-B and late

ANONYMOUS

GRO-B In particular the nature of my illness and how the illness affected me and the impact it has had on me and my family.

2.How Infected

1. I have a mild form of haemophilia but with complications. My doctor has always said that if something can go wrong with my health then it will. I have always lived life to the full, but if I have a bump I need to rest as it will cause a bleed. The bleed goes to my joints which causes stiffness and swelling which causes me to need rest. I have been treated with various blood products.
2. I believe the blood product which infected me was Factor VIII, but I don't know when exactly I was infected but it must have been between the late **GRO-B** and late **GRO-B**. I think I had the last Factor VIII in **GRO-B**.
3. I have mainly been treated at **GRO-B** Hospital in **GRO-B** by Dr **GRO-B** and there was a doctor called Dr **GRO-B**. It was **GRO-B** Hospital that gave me the Factor VIII. I was treated at **GRO-B** Hospital in **GRO-B** for a duodena ulcer in the **GRO-B**. I have had scans at the **GRO-B** Hospital in **GRO-B** (**GRO-B**), and had an operation on my knees in **GRO-B** Hospital; this was about **GRO-B** or **GRO-B** years ago. I know I went to **GRO-B** when I was much younger, and saw someone called **GRO-B** but I don't remember getting any treatment from there. I also had some teeth pulled when I was about **GRO-B** at **GRO-B** Hospital; I think I had some blood products given to me then. At one point I banged my ankle and I had a big bleed, I believe this was in the early **GRO-B**. I know I was definitely given Factor VIII to treat that.
4. I can't remember any exact dates when I was given the Factor VIII. I know I was given the Factor VIII, but I can't say exactly when. I was told about 5 years ago that I had been exposed to hepatitis C (HCV). I don't believe anyone has ever told me the full truth. The advice given to me by Dr **GRO-B** was only to avoid stress, but that's hard to do when living a life. I have been tested for lots of things over the years, HIV, hepatitis C (HCV), that

ANONYMOUS

sort of thing. I don't really trust the doctors. I do ask questions since they told me I had been exposed to it, but I don't know what to think.

5. I wasn't given any information before I was given the Factor VIII, or any other blood product I might have been given, of any possible risk of being exposed to infection from blood products. I have been infected with hepatitis C (HCV) because of the blood products I was given.
6. Dr [GRO-B] told me that I had been infected with hepatitis C (HCV) during an appointment at [GRO-B] Hospital. He spoke briefly about it and told me I had to be careful with my wife during intercourse, but then we always have been because of the haemophilia. At that time, you never questioned doctors; they knew everything. I do now as I'm older and wiser, but at that time the doctor was the expert. Dr [GRO-B] must have explained some things, but I don't remember much about it.
7. The haemophilia is just something I lived with, and I treated the information about hepatitis in the same way, I just got on with life and just hoped that it didn't get to the next stage. I was tested every six months and they kept an eye on me that way. I had the liver function test and thought if something was wrong they would get in touch with me. Part of my blood was sent away for further testing. Dr [GRO-B] told me about the hepatitis C (HCV) at an appointment, verbally. It was in the course of a conversation, as in, 'Unfortunately you have been exposed to hepatitis C (HCV).' He wasn't insensitive, we were given some information about the risks, I can't remember the exact details, but he did say we were to be careful during intercourse.

3. Other infections

1. I have been told there is a possibility I have been infected with Variant Creutzfeldt-Jakob Disease (vCJD). I have asked how things are going there, but for the time being I'm ok, nothing has happened. I had a second cataract operation some time ago, and Dr [GRO-B] who treated me, had said that there was an instrument he had put aside for me when I had the first one done, they

ANONYMOUS

couldn't use it on anyone else because of the risk of someone else getting infected with vCJD or hepatitis, and as it cost £3,500 they couldn't get rid of it. At the second appointment when I went to get the second operation he then said that I was alright and didn't have vCJD. This confused me so when I was next at **GRO-B** at the Haemophilia Centre I asked whether I had vCJD they said that I didn't have it, that I was not at risk any more.

4.Consent

1. I don't know if I have been treated or tested without my knowledge, I haven't been told that I was treated or tested after the fact. I'm not sure how you would know unless they told you afterwards, and I haven't been told, so unless my medical records say something different then I would say I haven't and there is nothing in my records to suggest that I have. I do know they were doing some type of testing, but I am not sure what they were testing me for. I knew I was being tested for some things, I think they did give me some information, but I can't remember what they said. When they gave me the treatment for the haemophilia I didn't know there was a risk of infection from what they were giving me. At one point I did give permission for my blood to be taken for some type of research, but I don't know what exactly they were using it for.

5.Impact

1. I have had a **GRO-B** which is why I retired from work. I'm not sure if **GRO-B** was because of my medical condition but it could have been a factor. The fact I have hepatitis C (HCV) is always in the background of my mind. When I think about it I think about my grandchildren. I want to see my grandchildren grow up, I have **GRO-B** grandchildren, and I want to be there and to see their lives unfold. I don't want to die before my time.
2. The hepatitis C (HCV) must have affected my physical health, but I'm not sure how exactly, it all goes on inside you, and I don't know what's happening

ANONYMOUS

inside me. I try not to think about it too much, I don't give myself time to think as I like to keep busy. But then occasionally I stop, and it hits me and that's when I get worried about what will happen to me. This is a disease that will kill you, and that worries me.

3. I have been told I have a fatty liver, I believe that may be as a result of being infected with hepatitis C (HCV). I have had a duodena ulcer, I think that was because of taking Ibuprofen for the pain. I have difficulties seeing a dentist. The local ones won't treat me at all and I have to go to the hospital to get any treatment. I'm not sure if the dentists know about the hepatitis C (HCV) or not, or whether they won't treat me just because of the haemophilia.
4. I have GRO-B boys but we haven't really talked about the whole situation that much as we are not that sort of family. But it has affected them, it is bound to have. They must think all the time, 'Dad's going to die'. There is always a thought in the back of my mind whether my wife will catch it too, whether the boys have caught it. We didn't get the boys tested, and as far as I know they haven't chosen to either. We did buy the house, with money from the fund, with the thought that if anything happened to me, at least they would have the house without a mortgage.
5. The stigma has been terrible. When people first find out their immediate thought is that I'm a druggie and that is horrible. Their impression of you changes when they find out. There was a nurse who was taking my blood, and her attitude was awful she thought the worst of me, that I had been doing drugs. I had to explain the truth to her, but why should I have to explain. People always think the worst of you. There are ignorant people out there, they can't touch you, but it does affect you mentally. I couldn't tell the people at work. I told them about the haemophilia, I had to – if anything happened to me, if I got an injury, I was relying on them to get me to the doctors quickly, so I didn't bleed out. But I could never tell them about the hepatitis, I couldn't tell them what was going on in my life, I couldn't get that close to them. Some work mates were horrible, and I knew I couldn't risk it as

ANONYMOUS

I didn't know how they would react. I still had to work with them, so it was safer not to say anything.

6. Being infected with hepatitis C (HCV) did not affect my education as it happened after I left school. It didn't really affect my job; it was the haemophilia that affected that, until I had the breakdown. The breakdown meant that I had to retire, I couldn't continue. It hasn't really affected me financially, except that I have had to pay to get to hospital appointments, and there have been transportation costs.
7. I think about the impact it has had on my life, but I just carry on. If you let it affect you then it will affect every part of your life and I won't let that happen to me. My biggest worry is how it has affected the people around me, my wife and sons, mainly. Sometimes I think it is better not to know and then I wouldn't have to worry at all, but on the other hand if you don't know you can't get the right treatment.

6.Treatment/Care Support

1. When I was having tests on my liver in GRO-B Hospital, done by a Chinese doctor, I think, there was some talk about going on a trial for hepatitis C (HCV). He then said that I couldn't be part of it as they would have to do a biopsy, but because that would likely cause a bleed because of the haemophilia there was no point putting me at risk, so I couldn't be part of the trial. I know I will have to go back for more liver function tests. I have had no other difficulties in getting treatment.
2. I haven't had any counselling or psychological support because of the hepatitis C (HCV) infection. I did have a bit when I had the breakdown, I saw the work doctor. As soon as he saw me he asked me when I would like to finish, and I was retired on health grounds. I saw the GP at that time too, but I haven't seen someone specifically about being infected with hepatitis C (HCV).

ANONYMOUS

7.Financial Assistance

1. A letter was sent to me, out of the blue, from the Skipton Fund about 15 years ago. They offered me a one-off payment of £20,000 and said that's the lot unless the hepatitis C (HCV) went to the next stage when there would be a further payment. I didn't have to fill in any forms or anything, just sign a statement that I would accept the £20,000 and I would waive my rights to any other compensation. A short while after receiving it I was talking to someone about my benefits (I have had care/mobility allowance since retiring from work on health grounds) and I mentioned the £20,000 to them. The person on the other side of the phone instantly said that I would not receive my payments because of it. I explained what it was for and they talked to their supervisor. I was worried at this point, but after about half an hour I got a call back and they said I was alright and could keep the money. I was quite relieved about this.
2. About two years ago I got another letter, I believe it was from the Skipton Fund again offering a monthly payment. I have received a payment of £385.17 monthly since then. I did not have to fill in any forms for this money. I don't think the money comes from the Skipton Fund any more. Its from GRO-B now, I think it is part of the GRO-B taking control of things like this, but I am not sure. I don't know why I have received this money and other people haven't. If it is good enough for me then it is good enough for everyone. Everyone should be treated equally.

8.Other Issues

1. I don't have anything else to say, except that it should not have happened in the first place. I don't think the doctors who actually gave me the infected products knew what they were doing, but someone knew something. Dr GRO-B did say to me that he didn't know and if he had he would never have given me the infected products. I have heard somewhere that GRO-B GRO-B down in GRO-B knew something. This idea that you buy the cheapest

ANONYMOUS

product because it is cheap is ridiculous; you should be buying the best product.

ANONYMOUS

Statement of Truth

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

Signed... GRO-B

Dated... 12.03.2019