

ANONYMOUS

Witness Name:

GRO-B

Statement No. WITN2550001

Dated: 14/12/18

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 and address are known to the Inquiry.

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2. I was born in the [GRO-B] area and grew up in [GRO-B] I moved to [GRO-B] in around [GRO-B]
3. At the present time, I do some [GRO-B] and [GRO-B] [GRO-B] for which I act as a [GRO-B]
4. I am [GRO-B] and have an [GRO-B] year old daughter.

2. How Infected

1. I suffer from Haemophilia A. I was misdiagnosed as severe 2% haemophiliac, (circa [GRO-B]) but only had bleeds when I had a heavy impact. This diagnosis was not corrected until [GRO-B] I believe that if my diagnosis had been corrected earlier it may have affected the way I was treated for bleeds but I am now diagnosed as very mild, 20% plus.
2. It is my understanding that I was first diagnosed when I was about 8 years old. My knee blew up badly. I was treated by having it put in plaster. I was in terrible pain for around 2 weeks. I was then diagnosed as being a haemophiliac.
3. In those days, the early [GRO-B] treatment was not very sophisticated. I was treated with plasma and bed rest.
4. I also received Cryoprecipitate at times.
5. I had a relatively normal childhood apart from that. I had the occasional bleed but was generally okay.
6. I believe I became infected with Hepatitis C after I had a car accident in [GRO-B] I had a bleed in my arm and right knee. I was taken to [GRO-B] Hospital and then transferred to hospital in [GRO-B] I was treated with Factor VIII. This was the first time I had Factor VIII.

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7. I had a terrible reaction to this. For a couple of days, I ran a very high temperature of over 100°. I can remember the nursing sister saying that she had seen several other people suffering the same reaction from the Factor VIII.
8. From then on I felt generally unwell. I felt very fatigued. Everything was a bit of a struggle.
9. My Consultant at [GRO-B] was Dr. [GRO-]. I would see him if I had a bleed. I probably only saw him 2 or 3 times in the 7 years or so before I was diagnosed with Hepatitis C.
10. During those years he had said to me that there was a risk of being contaminated with Hepatitis C and did I want a test? I effectively avoided the issue at that time.
11. I then recall reading about the contaminated blood scandal in the Sunday Times Magazine. Therefore, I asked for a test. The test came back positive. This was in [GRO-B]
12. Dr. [GRO-B] then suggested that I try Mono Interferon, which was the only treatment available to me at that time. The treatment consisted of 48 weeks of three injections per week and would cause me to suffer flu symptoms throughout the treatment. This treatment only had a 10-20% success rate and therefore I decided to wait for the next available treatment.
13. I was very wary about taking the treatment because I had been told how bad it would make you feel. I was feeling ill and could still just about work if I could pace myself. The Interferon would have caused me to take a year off. I was aware that there were new treatments being developed, so I avoided taking the Interferon treatments at that time.

3. Other Infections

1. I do not believe that I have received any infections other than Hepatitis C as a result of being given infected blood products. I have been tested for HIV but I am not aware that I have been infected with that at all.

4. Consent

1. I do not believe that I have been treated or tested without my knowledge or consent.

5. Impact

1. At the time of the car accident when I believe I was infected I had been running a small business as a GRO-B and had been doing, I thought, quite well. However, with me feeling unwell, it was too much, so I packed it in.

2. I worked GRO-B for a while. I helped run a bar. I did not work particularly long arduous hours. I worked in a wind surfing shop which allowed me to only work part time out of the summer months. I would often find myself falling asleep on the counter of the shop.

3. I became aware of a new treatment available called Pegylated Interferon and Ribavirin and enquired about this at GRO-B I was referred to the gastroenterology department where I was told that as my liver function test was not abnormal and therefore treatment was not available to me at my local hospital. I was told that I would be referred to GRO-B Hospital GRO-B where a Dr. GRO-B GRO-B was performing a trial with Pegylated Interferon and Ribavirin. I was told this was an expensive treatment but I pressed for it and was eventually accepted.

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4. I had to travel to **GRO-B** every 4 to 6 weeks. I must have gone about half a dozen times.
5. The effect of this treatment was that it made me feel really rotten. I had 48 weeks of treatment and then recovery. I could not do any work for about 18 months.
6. It made me very fatigued and breathless. Just walking upstairs in the house made me feel out of breath.
7. It was like having extremely bad flu all the time.
8. I underwent this treatment in **GRO-B**. Unfortunately it did not succeed.
9. A few years later, I was aware of a further treatment being made available. I again pressed for this. My Consultant, Dr. **GRO-B** **GRO-B** in **GRO-B** was very supportive. However, because I was not suffering any sort of serious liver problem, it seemed I was going to miss out on this new further treatment.
10. Finally, my doctor got me a meeting by video conference before a number of Heads of Departments of Hepatology. By now the treatments had been approved by NICE. I was desperate to get it because I was still struggling and still feeling ill and fatigued.
11. My plea to the Hepatologists fortunately proved to be successful.
12. In late **GRO-B** I started the new triple therapy, Pegylated Interferon, Ribavirin and Telaprevir. I had this treatment at the **GRO-B** Hospital.

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13. At 6 months into treatment I was told that I was marginal, so I was not yet clear from Hepatitis C. It meant that I had to have another 6 months of treatment.
14. During this time, I was again feeling very ill. I could not work, I was very anaemic. I was breathless, it was like having heavy flu.
15. The second 6 months was the worst.
16. I finished the treatment in the Autumn of **GRO-B** and fortunately, this time, I was given the all clear for Hepatitis C in **GRO-B**. This was a fantastic feeling. It was a huge weight off my mind.
17. Although I had not had major complications as a result of my Hepatitis C, for example, I had not had serious liver problems, I had always been worried about what might happen and it got me down and very depressed. It made me feel life is a great struggle.
18. Around all this time, my wife had been a huge support to me. During the time I was unable to work, she would be working. We managed to keep things together. However, I do wonder what might have happened. How life might have been different if I had never contracted Hepatitis C. I believe I could have managed to cope with haemophilia. It was something that never caused me a lot of incidents of significant problems. It was the Hepatitis C which caused me to feel tired, run down and ill. It was that, that caused me to give up my business in my early 20's and to gravitate towards less intense work and jobs.
19. It also meant that I was at times, very ill and could not give so much attention and energy to my daughter as she grew up. My daughter, like my wife, understood and was supportive of what I was going through, but I still regret that I could not do as much as I would have wanted with her.

20. In [GRO-B] I had been on treatment for a year and was the main carer for our [GRO-B] year old daughter whilst my wife was working to support us. My wife found this time extremely difficult, especially when the treatment proved unsuccessful. When I was told the treatment had failed, the doctor in London said new treatments were being developed and should be available in 5 to 10 years. It was in fact, 11 years and this was again, a very difficult time.

21. An example of not being able to do as much with my daughter as I would have liked when she was young was when one day I took my daughter to our local Zoo which was within walking distance whilst my wife was at work. One of the symptoms of my Hepatitis C was as well as extreme tiredness, I was feeling cold all the time and often chilled to the bone. On this occasion, I wore double clothing and hung a hot water bottle round my neck, disappointingly, what should have been a fun occasion for us both, turned into a trial, hopefully only for myself.

6. Treatment/Care Support

1. As stated above I had to battle hard to be allowed the triple therapy treatment in [GRO-B]
2. Dr. [GRO-B] at times has mentioned [GRO-B] to me. I have not taken this up. I did not fancy it and to be honest, I do not want to attend hospitals or doctors if I do not have to. My wife also works in the sphere of [GRO-B] so she has been able to give me good support and help when I have needed it.

7. Financial Assistance

1. In around [GRO-B] received £20,000 from the Skipton Fund. I became aware of the Skipton Fund through information given to me at the time in hospital.

2. The money came through during the first period of treatment I had with Pegylated Interferon and Ribaviran. During that time, I was unable to work, so it was extremely good timing to receive the payments.
3. I received a lump sum of £3500 on the 19th December GRO-B a further lump sum of £1250 on the 9th November GRO-B and a first monthly payment of £350 which started on the 13th February GRO-B I currently receive about £385.17 per month from GRO-B Trust. This is relatively recent I understand that I was on a database and so I was contacted about it and it was a relatively straight forward process to apply for and then to receive this payment.

8. Other Issues

1. For some years now I have been very grateful for the help and assistance of Haemophilia GRO-B and in particular their Chair GRO-B GRO-B She has always been extremely helpful and supportive when I raise questions or issue with her.
2. In one sense, I have been fortunate in that I have not suffered extremely serious complications with the Hepatitis C such as serious liver damage. However, that in itself has been a particular problem for me, as it has meant that I have had to battle and press extra hard for treatment and support.
3. I genuinely feel that my life has been blighted. Although I was a haemophilia sufferer, life was going well and I set up a thriving business in my early 20's. However, my Hepatitis C blighted most of my adult life. It restricted and limited me. The years when I had treatment were terrible times when I was fit for nothing. Without the support and help of my wife and the understanding of my daughter, I do not know what I would have done.

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4. I have been virus free for over 4 years and feel well. However, I still suffer tiredness from Hepatitis C which I continue to manage on a daily basis. It means that I am unable to work normally and still affects social activities and holidays. I saw my doctor last year and he gave me blood tests for the usual suspects which showed nothing and he suggested post viral fatigue. I am disappointed there is no support for this and I have now resigned myself to this not improving.

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Statement of Truth

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

Signed..

GRO-B

Dated.....

14 Dec 2018