

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2474001

Dated: 17th February 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF **GRO-B**

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12<sup>th</sup> 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. I am married and have **GRO-B** children and **GRO-B** step children. I am in my last year of my **GRO-B** at **GRO-B**
2. I intend to speak about my Father, who contracted hepatitis C (HCV) from being given Factor VIII in the early 1980's.

### 2.How Infected

1. My Father was infected by Factor VIII, I believe that he was infected in the late 1970's/early 1980's.

## ANONYMOUS

2. My Father has severe haemophilia A and to the best of my knowledge he was infected with hepatitis C (HCV) through Factor VIII given to him during a bleed that happened in [GRO-B] (Either at [GRO-B] hospital or the [GRO-B] [GRO-B], I cannot recall which of these two). He was seen in both of these hospitals amongst others.
3. At the time, he was under the care of Dr Korn, a haematologist at [GRO-B] [GRO-B] in [GRO-B] as well as frequently visiting both [GRO-B] hospital and the [GRO-B] in [GRO-B] and another hospital in [GRO-B] of which its name I cannot remember. To the best of my knowledge, my Father was not provided with advice beforehand about the risks of being exposed to infection
4. Dr Korn informed my Father around 1996 that he may have been infected by the Factor VIII that he received years prior, he then tested for HCV, HBV and HIV. The test for hepatitis C (HCV) came back positive, but the other two negative. Dr Korn was shocked that the test for HIV was negative and subsequently repeated the test numerous times. Dr Korn's shock led my Father to believe that he had previous knowledge that the Factor VIII was infected.
5. There was no information or advice offered to my Father at the time. He should have been offered information and support when he was informed that he had contracted hepatitis C (HCV). He went off the rails when he was told and within his close family a total of [GRO-B] (including him) all suffered with haemophilia. All of which, except for him, have since passed away so of course he was scared.
6. After my Father was told that he was infected, my Mother got tested for hepatitis C (HCV) and I remember my sister and I as young children having

## ANONYMOUS

vaccinations for hepatitis B (HBV). My Father was fearful at this time that he had passed the virus on to my Mother and to my Sister and I.

### 3.Other infections

1. Hepatitis C (HCV) is the only infection my Father has received as a result of being given the infected blood product to my knowledge.

### 4.Consent

1. I believe that my Father was treated without being given adequate or full information, because they knew the product was contaminated and they didn't tell him.
2. My Father's haemophilia A was also treated for the purpose of research, as he was given pig's blood in a hospital but I'm unsure which hospital.

### 5.Impact

1. The mental effects on my Father as a result of being infected with hepatitis C (HCV) have been great. I believe that he needs counselling as this has had a massive effect on him. He's a very positive man, he still works full time and he's the loveliest man in the world, but he will not tell my Mother, my Sister nor I the full truth so as not to upset us. At work people used to call him names, and that upset him, and I remember as a child hearing him arguing with my Mum about it before speeding off in the car. This Inquiry is also affecting my Father's mental health, as it is bringing everything back for him personally. People in GRO-B knew that my Father had haemophilia before this came out, so when the connection was made and was heavily publicized people started staying away from him thinking that he had HIV.
2. A few years ago, he was given Interferon, and during that time he became very depressed and low, and due to his weakened immune system, arthritis and so on, he couldn't carry on taking the Interferon. The promise of the

## ANONYMOUS

success of Interferon had really raised his hopes, so then to have to stop taking it for health reasons was arduous on him mentally.

3. The hepatitis C (HCV) is dormant in my Father at the moment, however the fact that it could become active at any moment is a constant source of worry for him and it is always in the back of his mind and this takes a toll on him. Due to contracting hepatitis C (HCV), my father has an enlarged liver which is monitored regularly through scans and blood tests. I would also say that my Father suffers from depression and anxiety as a result of hepatitis C (HCV), however he would never admit that.
4. My father's hepatitis C (HCV) has mainly been dormant, however a few years ago it became active, and that is when he was given the Interferon. After he had to stop taking the Interferon because of the aforementioned health issues, the virus somehow returned to being dormant, even though the doctors told us that the dose of interferon received would not have been enough to kill the virus.
5. My father is aware of a new treatment going on in GRO-B but it is only offered on GRO-B therefore he can't have it. Also, the new treatment only works on active cases of the virus and my Fathers' isn't. But knowing about this treatment raised his hopes before they were knocked back down again. The only treatment my Father has received for the hepatitis C (HCV) is the Interferon, however he did not manage to take the whole course. My Father has had difficulty accessing the aforementioned new treatment in GRO-B due to it not being available on GRO-B I believe that he should be offered this treatment should the virus become active in the future.
6. The mental effects on my Father as a result of being treated with Interferon were great. He came home from work one day and broke down in tears. I've never seen my Father cry before, it was awful. Initially, my Sister and I were urging our Father to take the Interferon, however, two weeks into the treatment we were the ones that were urging him to come off it as he was in so much pain.

## ANONYMOUS

7. My Father's infected status has not impacted upon his medical treatment per se, but has impacted upon the way he feels he is treated. As a GRO-B I know from experience that every healthcare personnel on the ward will be aware of my Father's hepatitis C (HCV), and I believe that this causes embarrassment to my Father as he is such a private man. A recent example of this is around two weeks ago we had to call an ambulance for my Father, and the as one paramedic was inserting an IV line, the other said "you need to put gloves on", the paramedic did not hear so he had to repeat it. They only said this because he had hepatitis C (HCV) and if I noticed it my Father certainly did too and again I can imagine that although this was a necessary thing to say, it caused him shame.
8. Being infected with hepatitis C (HCV) has certainly affected my Father's private family and social life. When the scandal was revealed on the news in the 1980's he didn't leave the house or go to work for a few weeks because people thought he had HIV. He was initially extremely worried that he had infected the whole family with hepatitis C (HCV). My Mother was upset as she thought that she had also been infected and that she had subsequently passed it on to her children. It also had an effect on the extended family. My Father's sister was worried at the time that she could have been a haemophilia A carrier, and subsequently she was scared to have children in case they carried it too, but she was ashamed to feel this way as it upset my Father. Although he did not drink a lot before he was infected, he did occasionally go to the pub with his friends. This stopped immediately after he was diagnosed, so he lost that social side of spending time with his friends. People stopped coming over to the house as they did before, and he became scared of seeing people that he knew because he feared what they would say.
9. Initially, the diagnosis didn't largely have an impact on my mental health, or private/social/family life. However, I fell pregnant at the age of GRO-B and we knew that I was carrying a boy so the haemophilia A could be passed down. This is when I really became aware of it. Also, since I have been in the health

## ANONYMOUS

care profession, I have become much more aware of what hepatitis C (HCV) can do to someone. I see people who have cirrhosis and I know what it does to people, and it's worse because my Father has this illness through no fault of his own. I have my own children now, and I know what it feels like to lose a grandparent, I don't want them to have to go through the same thing because of this. It affects me as well because I'm his first point of contact, I take him to his hospital appointments and I'm the only one he'll talk to, and it's hard for me to see him upset.

10. The stigma of the diagnosis has had an effect on my Father. He gets really embarrassed, he doesn't like people knowing that he has hepatitis C (HCV). He hates having to tell medical professionals that he has it, but he knows he has to. He gets so embarrassed he can't say out loud that he has hepatitis C (HCV). The stigma perceived by other people also affected him because once word got out, GRO-B and as a GRO-B GRO-B it was the most crucial part of his work, and it was being hindered by the fact that he had been infected with hepatitis C (HCV), and it wasn't his fault.
11. The infection has not stopped my Dad from working; work is his life and that is what keeps him going. Only in that short period right at the beginning did he stop going to work due to the stigma and the name calling, whilst people stopped GRO-B from him. He also had to stop work for a while with the Interferon treatment. He says now that he will not have any further operations because he can't afford to lose 6 weeks' pay, but deep down I think it's more to do with the fact that he's scared.
12. My Father's infection has affected my education to some degree. I remember being on GRO-B at a GRO-B when a man the same age as my Father died from cirrhosis. I remember seeing how yellow his eyes and his skin were, and it was very upsetting for me because it really shows you what this can do to people. It was worse because that man was an alcoholic, so he had a choice to drink or not, dad did not have the choice whether to be infected with hepatitis C (HCV) or not.

## ANONYMOUS

### 6.Treatment/Care Support

1. To the best of my knowledge, my Father was not offered any treatment up until a few years ago when he took Interferon, however he didn't have any difficulties accessing that treatment. The treatment in GRO-B at the moment however, if the hepatitis C (HCV) were to become active again, he would have problems accessing that as it is not available on GRO-B
2. He has a very good haemophilia nurse in GRO-B he's lucky to have her as she's aware of how he was infected and so on and is very good with him.
3. My Father was given counselling many years ago, but I'm not sure if it was because of being infected or because of the hip replacement that went wrong. I have never been offered counselling, but have also never sought any. My Mother should have been offered counselling, she will enhance on this in her statement. My Father has not been offered any counselling recently to my knowledge.

### 7.Financial Assistance

1. My Father was made aware of the Skipton Fund, but he has only received one payment, I am unsure as to how the whole thing came about. I believe that it's wrong that to get the next payment he would have to be gravely ill.
2. I believe that the financial assistance that my Father has received does not suffice. He's contracted this infection through no fault of his own, and he has to pay for many things as a result from his own pocket. An example of this recently is he had to build a downstairs bathroom with an accessible shower in his home due to his immobility

## ANONYMOUS

3. I have never received any payments from any Trust or Fund, however I would never think to seek it because it's my dad that should be receiving the financial assistance, not me.

### **8. Other Issues**

1. My Father was given Factor VIII to take home with him from hospital once. He did not take the Factor VIII after returning home. Due to Dr Korn's shock that he had not contracted HIV, my Father is convinced that the HIV was in the Factor VIII that was given to him to go home, which he didn't take. This would suggest that Dr Korn knew that the blood product was infected, hence his surprise. This really hurt my Father as Dr Korn was very good to him, and they had previously grown to be friends, with Dr Korn attending my parents' wedding and everything. As a result, my Father was unsure whether to attend his funeral or not when he recently passed away.
2. Also, there is a haematologist that I know of, who also suffered from haemophilia, and I have been told that the consultants haematologists warned all the other doctors and nurses not to give him the Factor VIII because they knew it was infected. This leads me to think that they all knew and that they were protecting their own only without a care for the other patients.



# ANONYMOUS

## Statement of Truth

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

Signed.....

GRO-B

Dated.....

17.2.19