

Witness Name: GRO-B

Statement No.: WITN2294001

Exhibits: none

Dated: 18<sup>th</sup> 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 5<sup>th</sup> November 2018.

I, GRO-B, will say as follows:

### Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1941 and my address is known to the Inquiry. I am a self-employed GRO-B GRO-B. I intend to speak about my contraction of Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me.

## Section 2. How Affected

2. I am a haemophiliac type B. This is also known as Christmas disease. My younger brother GRO-B was also a haemophiliac. The condition is genetic and passed down from my mother. At that time there was no treatment for the condition. If I suffered a bleed, I had to rest in bed. My haemophilia is classed as severe, although my brother's condition was far worse than mine.
3. As a child growing up if I had a bleed, I would receive bags of blood plasma. This had factor IX in it but you had to have volumes of it and it was very time-consuming. In the 1970s, Dr Forbes at the haemophilia centre at Glasgow Royal Infirmary, informed my brother and me that there was a new treatment. This new treatment was an injection of factor IX. This new treatment was revolutionary to my brother and me.
4. In August 1977, I was taken into Glasgow Royal infirmary as I had a fish bone stuck in my throat. I was on Ward 3 at the hospital. I was under the care of Dr Forbes. I was kept in hospital for about two days. This fishbone eventually dislodged itself nevertheless; I had to receive factor IX blood products. This is when I believe I was given contaminated factor IX blood products.
5. Professor Charles Forbes told my brother and me about the new treatment of factor IX by injection. I remember I asked him if there were any risks to the injection. He said "Not really". He did explain that I could get an allergic reaction. He also said that there was a risk of a type of hepatitis. I remember at the time there was a lot of publicity about people dying with hepatitis B. Hepatitis B was associated with drug users. He said "Don't be alarmed, it's not the hepatitis you read about in the papers". He said the effects of the type of hepatitis we might develop would be the equivalent of a stomach upset. When I had the factor IX blood products whilst I was in

hospital, I was not informed of the risk of being exposed to infection. I had already had the conversation with Professor Forbes beforehand. As a result of being given contaminated factor IX blood products I contracted hepatitis C.

6. At some point in the 1980s, I was told by Professor Gordon Lowe that I had had hepatitis B but that the infection had cleared itself and I was now cleared of it. In the early 1990s when I was in my early 50s, I attended at the haemophilia unit for a routine appointment. I saw Professor Gordon Lowe. He told me in "You have been infected with hepatitis C". He made it very clear to me that I had contracted hepatitis C as a result of being given infected blood products.
7. Professor Lowe told me that the infection was ongoing in my liver. He said my liver functions were abnormal. He did not make it sound too serious. I do not think he knew my prognosis himself. He said "You might get ill or you might not".
8. Professor Lowe did explain to me that the hepatitis C could be passed on to others. He told me that if I was to marry and have a child that I could pass the infection on to my wife and child. I am a heterosexual man but I was not married or in a sexual relationship at that time. He also told me that I could pass the infection on through blood-to-blood contact. I think adequate information was provided to understand and manage the infection.
9. I believe I was told I had hepatitis C as soon as it was discovered.
10. The only view that I have about how I was told I had hepatitis C was the uncertainty about the prognosis. I did ask Professor Lowe if there were any treatments. He told me that there was but it could have severe side-effects. He said the treatment involved anti-viral drugs. He said that because of the side-effects each case had to be carefully weighed up as to whether the treatment was offered. In the

circumstances I declined treatment until a new drug with no obvious side effects became available in 2019.

### **Section 3. Other Infections**

11. I did not receive any other infection or infections other than hepatitis C as a result of being given infected blood products.

### **Section 4. Consent**

12. Every six months my blood was taken at the haemophilia clinic at Glasgow Royal infirmary to test my liver functions. My blood was obviously tested for hepatitis C without my knowledge or consent. As a haemophiliac, I have my bloods taken on a regular basis. I was not given any information that it was being tested for anything else. I do not know if my blood was being tested for the purposes of research.

### **Section 5. Impact**

13. I feel I have been one of the lucky ones in that I had hepatitis C for 40 years but I had no physical side-effects.
14. If I had not been told that I had hepatitis C I would never have known. I have been able to lead an active and normal life.
15. Mentally, however it has had a huge impact. Professor Lowe couldn't tell me if I would get ill as a result of contracting hepatitis C. This has always been on my mind and has made me depressed at times. I liken it to, if someone told you your name is on a list of people who terrorists are proposing to assassinate. You have not been assassinated but it would be a constant worry, always looking over your shoulder. That is how I have lived for many years, always

wondering if the hepatitis C would become active again thus shortening my life.

16. I did not get any further complications or conditions as a result of my infections.
17. When Professor Lowe told me I had hepatitis C and mentioned the treatment I decided against it. I was feeling fit and well at the time. I was also looking after my elderly mother. I did not want to have severe side effects that might debilitate me, I decided I would take the treatment if my condition deteriorated.
18. I lead a normal, active life. I continued to go to Glasgow Royal infirmary for six monthly check-ups. My liver functions were abnormal but not seriously abnormal.
19. In 2018, I was told by Dr GRO-D, who was in charge of the liver unit at Glasgow Royal infirmary, that there was a new treatment available. He told me that there were no side-effects. The treatment was in tablet form. I cannot remember the name of it.
20. I did not face any difficulties or obstacles in accessing this treatment.
21. I do not believe there were any other new treatments available. If there were, I was not informed of it. I had no mental or physical side-effects from the treatments I received.
22. I remember after I had finished the course of treatment, I found a leaflet regarding the drugs I had been taking. On the leaflet there was a warning saying that if a person had had hepatitis B in the past they should not take this medication as there was a risk I could contract hepatitis B again.

23. I remember I spoke to Dr **GRO-D** and Professor Campbell Tait, who was the head of the haemophilia unit, about this. I raised with them my concerns regarding the medication I had been given. I was assured the risk of getting hepatitis B was very small. They said it had only affected a small percentage of people. I remember being angry that I had not been told about this risk when I was offered the treatment. I didn't take this matter further.
24. My infected status did not impact upon any medical or dental care for any other conditions.
25. Before I was told I had contracted hepatitis C, I lead a relatively normal life. I had to live with my haemophilia so I was always careful not to injure myself for fear of excessive bleeding. When I was told I had contracted hepatitis C, I continued to live a relatively normal life. I made a conscious decision not to get involved in any sexual relations for fear of infecting a partner. I was in my 50s at the time so this was not a big issue for me. I was very careful around other people and conscious that I could infect them.
26. My late father, mother and brother and I were a very close family. I wasn't really one to socialise, my haemophilia meant I avoided sporting activities and discos as I grew up, for the fear of sustaining an injury that for me and my brother could prove fatal.
27. I am aware of the stigma associated with the diagnosis of hepatitis C. It is linked to AIDS which was well publicised and as a fatal infection associated with homosexuals. I live in a small town where everyone knows everyone's business. This can be a good thing but can often be a bad thing. I did not broadcast my infection because of the stigma. Although, inevitably people got to know.
28. 

<b>GRO-B</b>	
<b>GRO-B</b>	This involved eating a

small piece of bread which depicts the body of Christ and drinking a small amount of wine from a chalice. The chalice was passed along to others. I remember on one occasion it was suggested that we should all drink from a separate cup to avoid the risk of getting HIV. It was clearly aimed at me. I was so embarrassed.

29. My contraction of hepatitis C did not have an impact on my family members. My brother GRO-B had himself contracted hepatitis C through being given contaminated blood. Miraculously for him, his infection had cleared up through his own immune system.
30. When I hear of other people's circumstances around the financial effects of contracting hepatitis C, I feel very fortunate. As I did not have any physical symptoms, I was able to work. I have made a successful business GRO-B. I am in my middle 70s and I am still working.

#### **Section 6. Treatment/Care/Support**

31. I have never had any counselling or psychological support as a result of being infected with hepatitis C. I have never been offered counselling or psychological support.

#### **Section 7. Financial Assistance**

32. I am a member of the haemophilia society. It was through the society that I found out that financial assistance was available in the late 90s and early 2000s. I contacted the Skipton fund, they sent me a form and I filled it in. Six months later, I received a lump sum of £20,000. In 2016, I received a further payment of £30,000 from the Scottish government.

33. The process of applying for financial assistance was quite simple. It just involved me filling a form in. I did not encounter any difficulties or obstacles.
34. There were no preconditions I remember imposed on the making of an application for financial assistance.
35. My observations on the financial assistance I received are that it was insignificant compared to what people in Ireland and America received for having been contaminated by infected blood. The money was ex-gratia and therefore no one what was held accountable. The people responsible should be charged, at the very best with gross negligence and at the very worst with misconduct in a public office with the maximum sentence for that offence being life imprisonment.

#### **Section 8. Other Issues**

36. I do want to remain anonymous in this enquiry.

#### **Statement of Truth**

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

Signed

GRO-B

Dated 18 APRIL 2019