Witness Name: GRO-B
GRO-B
Statement No.: WITN2153001
Exhibits: WITN2153002-007
Dated: 8th June 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 5th November 2018.

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

Section 1. Introduction

1. My name is GRO-B My date of birth is the GRO-B 1981. My address is known to the Inquiry. I am living in my own home and working. I intend to speak about my infection of Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and I and our lives together. I wish to be anonymous for my statement. GRO-B GRO-B GRO-B

Section 2. How Infected

2. I am diagnosed with Von Willebrand's, I was diagnosed with it in 1983 and it is considered severe.

3. I don't know the names of the products I received, as I was a baby. Mum tells me I received Factor VIII. The first time I received this, Mum tells me it was the wrong treatment. Factor VIII is used for both Von Willebrand's disease and haemophilia but we understand there are different components used for people with haemophilia and people with Von Willebrand's. I was given the wrong one because the doctors thought I was a haemophiliac. When it didn't work, my blood was retested and the Von Willebrand's was discovered. I have received haemate P and cryoprecipitate, I have also had DDVAP and tranexamic acid. I had a blood transfusion when I was nineteen months old and I had another blood transfusion when I had a gastrointestinal bleed in 2007.

4. I was being treated both at the Royal Infirmary, Lauriston Place, Edinburgh, where the hospital appear to have taken bloods when I first arrived and the GRO-B Hospital in GRO-B Edinburgh. Mum has been unable to locate records made on the exact day I received the infected products. She has located a Discharge Summary written some days later. However the record keeping may not be completely accurate. Mum and Dad would assess that it was in July1983 when I was infected, during my first Factor VIII treatment. There is a note on my medical records that refer to me being transferred from GRO-B for treatment on the 15th July 1983. I produce this note in evidence and refer to it as **WITN2153002**. There is also a letter from a clinical assistant that states I would have acquired the hepatitis C prior to 1985. I produce this letter in evidence and refer to it as **WITN2153003.**

5. It is only in the last few years I have realised in full, that it has been Hepatitis C in my blood. I always knew there was something wrong with my blood, but I didn't know full details. I was about thirteen years old when I was diagnosed which Mum tells me is 1994. I don't remember being diagnosed fully. Mum tells me that there were two meetings in March 1994. It was Dad and I during the first meeting

which was at the old Royal Infirmary, Edinburgh. There is a letter in my medical notes that refers to this meeting. I produce this letter in evidence and refer to it as **WITN2153004.** I can remember there were doctors there who spoke about how they were going to treat me and what the plan was. I don't remember much else. I remember feeling uptight and a bit worried. I didn't realise the full impact, of what Hepatitis C was then and I still don't. I didn't have a lot of health problems when I was in primary school or anything. I had my normal bleeds but I was healthy otherwise. I find it hard to remember as I was so young. I had psychological problems when I was younger, which left me with problems making friends at school. **GRO-B**

GRO-B

6. When I was diagnosed I don't remember the information I was provided. Mum missed the first meeting as she wasn't well that day. She went to the second meeting because she wasn't happy and she wasn't happy the way the meeting was conducted. She wanted to find out more about hepatitis C. There is a letter in my medical notes that relates to this. I produce this letter in evidence and refer to it as **WITN2153005**. Professor Hayes was there, who was very nice, but there were a lot of students there. Mum remembers that the students were literally glaring at us, Mum didn't like that. It is a sensitive subject and trying to process information, we didn't want a lot of strange faces and students at that point. As Mum can recall, the focus was on the treatment and the condition. They said my count was lower than a lot of others and we shouldn't worry. Mum says I was agitated at this meeting.

7. I don't know if Mum and Dad received information about stopping the spread of infection.

Section 3. Other Infections

8. Mum tells me I have received a letter from the Department of Health saying that I am at higher risk of contracting variant CJD. This letter

was sent to Mum and Dad years ago, but there is no indication that I have had blood from anyone who has died of VCJD. That is something I still have to mention however, when applying for things like travel insurance. It is also something which I would need to tell a potential partner and I know I would need help doing this. I worry about this and the potential outcome. There is reference to my risk of vCJD in my medical notes. I produce this record in evidence and refer to it as **WITN2153006.**

Section 4. Consent

9. I know that the doctors would take a lot of bloods from me but I don't know what they were testing it for. They were testing my liver counts previously and no one told Mum and Dad that they wanted to test me for Hepatitis C. No one ever said to them, here is a blood product but there is a chance you could get HIV or Hepatitis C from it.

10. I am not aware of being tested for research, but the reality is, I wouldn't know this either way.

Section 5. Impact

11. Through my childhood, teens, twenties and part of my thirties I have been unhappy. I was comparing myself to other people a lot, I didn't want to go out and felt uptight a lot of the time. I have found it hard to form relationships with any potential girlfriends. Some of my feelings can be related to the treatment I went through and it is now established to be linked to Hepatitis C. My Mum GRO-B discusses this in detail, in her statement. I can't remember physical symptoms but it was a long time ago.

12. GRO-B GRO-B There is a strong chance Hepatitis C and the treatments for it have GRO-B . GRO-B GRO-B still play a lot of things over in my mind.

13. Mum and Dad kept a lot of the information around Hepatitis C, hidden from me. I was told that no one was to touch my blood. I felt like I had a temper of a two-year-old at points. I would get angry at someone for no reason, which was very difficult. I would play a lot of things over in my mind, which was also upsetting. As I already said I still do have problems.

14. Mum tells me I was on interferon treatment the first time in 1994. I have had three different courses of treatment. The treatments caused me to have more mood swings and increased my negative thinking. Treatment of interferon lasted 21 weeks. I had a 2nd course of treatment when I was about 20. Mum administered my injections that time and they were sore and stingy. The 2nd treatment was October 2003, when I received interferon and ribavirin, which left me feeling unwell all the time. There is a letter on my medical notes which details the treatment I received. I produce this letter in evidence and refer to it as **WITN2153007.** I can't remember how I felt the first time I went through treatment but Mum discusses what she can recall in her statement.

15. The third treatment I felt good the first 2 weeks, then felt completely emotionless. I feel the impact of this on my emotions today. I did say on several occasions that if the treatment didn't work the third time, I wasn't going to go through it again. Mum still requests annual check-ups, which is appropriate. It is a new thing and should be monitored. The thing about the medical profession, they are focusing on the liver. They aren't considering other parts of the body. The virus can lie dormant in other areas including the brain and not come out for many years. When I found out that I was clear of the virus I felt ok. I can't remember exactly how I felt though. My big thing is that it affected my emotions and the treatments were very difficult. I go and visit with Grainne, one of the Edinburgh Royal, counsellors. She is fantastic, it is something that I could have done with years ago. She has given me great breathing exercises and great tools to manage difficult moments. It has taken me to a better place. Although I still have outbursts and negative thoughts.

16. I get check-ups from the community dentists but any treatment that could result in a bleed takes place at the Royal Infirmary Edinburgh as I require treatment beforehand.

17. GRO-B has been the main reason I have struggled in my education, GRO-B GRO-B I don't know if the Hepatitis C has caused or been a contributory factor in this as Hepatitis C can affect other organs, apart from the liver GRO-B

18. When I was on my third round of treatment I was able to work through this. I am working full time GRO-B GRO-B GRO-B When I got the job, it was through a scheme to assist people with difficulties into work; the person who arranged it checked with relevant authorities that Hepatitis C did not require to be disclosed. She assisted me to complete the form. I have never put anyone at work at risk of infection. I am careful. My employer is aware of my bleeding disorder.

19. For me, the biggest impact has been around relationships. It makes it difficult for me to form a relationship with any potential girlfriends because I have to disclose that I have been infected with Hepatitis C. I do have good friends now though. I have had a lot to cope with in my life, I feel like I am only now, able to grow up fully and live my life now I am clear of the hepatitis C. I am able to put my feelings into words with the support of my family and with Grainne. I am much happier now than when I was in my early 20s and teens. I meditate a lot now and I am looking online to meet a girlfriend. Things are moving forward now. Although it still isn't easy. I have to tell a partner if I get one, about Hep C and VCJD.

20. Mum and Dad have been upset and angry about what has happened to me and they have always supported and helped me throughout the years. They still do.

Section 6. Treatment/Care/Support

21. The help from Grainne, from the Royal Infirmary Edinburgh, now is fantastic, I believe she is the best. This is support I would have greatly benefited from years ago. It is only now I am realising the full impact of everything emotionally. Psychological support would have probably helped the whole family. I was able to access this support with self-referral at the hospital, normally if you ask for psychological support through your GP you have to wait over a year for support but I was able to see her straight away. Mum arranged the self-referral for me.

Section 7. Financial Assistance

22. My parents have assisted me with this. I am not involved with the financial applications directly, please refer to my mum GRO-B GRO-B statement for details on this.

23. Financial assistance has helped me, but I should have received compensation years ago.

Section 8. Other Issues

24. Mum and Thompsons Solicitors also have copies of my records. My mum's statement provides much more detail about my Hep C infection, due to the fact I was so young when it happened GRO-B GRO-B I suffered.

Statement of Truth

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

Signed GRO-B

Dated 27/01/2020