Witness Name: GRO-B

Statement No.: WITN0279001

Dated: 26 November 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth and address are known to the Inquiry. I am married with 2 children, a boy aged 9 and a girl aged 4. My wife and I have been together for 13 years and have been married for the past 5 years. I intend to speak about my Hepatitis C infection. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and our lives together.

Section 2. How Infected

 In GRO-B 1987, I was 9 months old when I suffered burns to my body by accidentally pulling a kettle of boiling water on to myself. I suffered burns to my chest and arms and was taken to Manchester Booth Hall Children's

Hospital in Manchester and needed a blood transfusion. I was told by my mother that I was given plasma treatment for the burns, however she remains unsure as to what exactly I was given. The entire process was unclear and very rushed at the time.

3. In 1997, aged 9 years old I received a letter from Booth Hall Hospital addressed to me (not my parents). The only reason I knew it was a letter for me was because I thought it was a love letter as it had at logo with two hearts and a crown on it (the logo of a blood charity). I can't remember what the letter said; if I'm honest I just blanked it from my mind and gave it to my mother. I remember vaguely it said something about the hospital messing up and that I could have potentially contracted hepatitis C as a result of that. The recommendations suggested that I go back to the hospital and get myself checked. It took a while, but just before my 9th birthday I was informed I have Hepatitis C.

Section 3. Other Infections

4. I do not believe I have contracted any other infection as a result of the blood transfusion I received in 1987.

Section 4. Consent

- 5. I do not believe I have been tested or treated without my parents' Knowledge and then later in life my consent
- There is no way my mother would have consented to my treatment had she known of the consequences. Till this day she still blames herself and says she would never have given consent without adequate knowledge.

Section 5. Impact

7. Having Hepatitis C growing up was never nice. I couldn't tell anyone and a lot of it was not knowing what was wrong with me. I felt like I missed out on

my childhood, as I couldn't do what my other friends would do. I was told I'm not allowed to do things like contact sport, have unprotected sex or have tattoos.

- 8. I was just a child when I found out I had hepatitis C. When I was old enough to realise what I had, life changed. I became a 30 year old at the age of 12. Even, if I cut myself, I would clean myself and wouldn't let anyone near me. I couldn't even go to the dentist because I was too afraid and didn't want people to know. It's a situation I wish I never had to find myself in and a situation I should never have been put in I should have been allowed to be a child. When you are faced with the prospect of dying you grow thick skin.
- 9. No one spoke to me about my condition, everything was explained to my parents. It wasn't until I reached high school, I realised there is something seriously wrong with me. I didn't know if my teachers knew or not, you were never told so I didn't know who was aware and who was not. I know my two brothers were unaware. I didn't speak to my mum and dad about it either as I felt stupid. My doctor told me I'd have a life expectancy of 18-30 years, this has always stuck in my head. It felt like I had a death sentence hanging over me. I have had three liver cancer scares, and they were hard, especially the last one.
- 10. Having Hepatitis C meant I couldn't get a mortgage because no one would agree to cover the insurance element of the mortgage. Even if I were to get a mortgage, the burden would then fall onto my wife in the event of my death.
- 11. I do travel but I can't get travel insurance for the same reason, which puts me at even greater risk. It is hard to enjoy yourself when you are away when you are in fear of something happening to you.
- 12. Having hepatitis C has also impacted my family. When my wife was pregnant she had to go through extra tests and undergo the process of

explaining my history to every doctor. One of the most distressing meetings she has had was with a health visitor when my wife was pregnant. The health visitor turned around and said that she ought to speak to me about changing my lifestyle with drugs and alcohol (suggesting that's how I contracted Hepatitis C). As a result, she finds it very distressing to go to the doctors. I've had many people who have walked away from me like my friends, but the worst comments have come from the health professionals as they jump to conclusions straight away.

- 13. It's been really difficult bringing up my children. For example, if they cut themselves I can't help because I am afraid of giving them something. It's been really hard on my wife who has had to deal with bringing up the children, mostly on her own. This has been due to me being on many treatments whilst they were young and being bed bound whilst ill. I did not want the children to see me as ill as I was.
- 14. The stigma attached to hepatitis C made it really hard to form and maintain a relationship. I wasn't able to tell all my friends, because of the stigma. It was treated like HIV. People thought you can catch it and as a result, I had to grow up quicker than others and couldn't enjoy being a child because you had to deal with things most kids didn't have to in their whole lifetime.
- 15. I was referred to as the golden boy at home and treated differently to my other brothers. Everyone thought it was because I was the first child, but it wasn't until years later they all realised why I needed special care. My mother and father knew, but my brothers didn't know I had hepatitis C until they were old enough to understand. The hardest thing was not being able to speak to my parents about it and at many times I felt alone. I didn't want to ask my mum questions simply due to the fear of knowing the answer-that I could die. I think I preferred not to know.
- 16.I have a select group of friends who know, but I still find it hard to tell people because of the stigma attached to these infections and lack of knowledge about them. Presumptions will be made. My wife's family only know

because they helped with the kids when my wife went to work. They would also look after me when GRO-B was at work and I was undergoing treatment. The only reason I told my friends was because I needed someone to look after me when GRO-B was busy looking after the kids or in the event that something happened to me whilst I was out with them etc. My best friends had to know for my own safety – just so that they could stop me from drinking alcohol. I was rebellious as I was told I was going to die, so I didn't care.

- 17. When my wife and I met, I was 19 and she was 16 years old. I didn't tell her until things started getting serious. It was in fact my mum who made me tell her and I felt we were serious enough for me to tell her. It was hard to tell her, but she was very understanding. A few of my friends stopped talking to me after I told them, and till this day I still don't speak to them.
- 18. Hepatitis C has also had a major impact on my career and aspirations. There are several things I wanted to do growing up that I couldn't. I felt my dreams were taken away from me when I was 9 and there was nothing I could do about it. I had trials for GRO-B Football Club and passed the first round but couldn't pursue it further. This was devastating for me.
- 19. My greatest teenage aspiration was to join the Army. My father and my stepfather were both in the Army. I wanted to join the Army even more than I wanted to be a footballer as I've studied it for as long as I can remember. It was my life long dream and I wanted to carry on the family tradition. I went to the recruitment centre at the age of 16 and I passed all the tests but I had to tell them about the Hepatitis C. When they found out they said I couldn't join the army, which absolutely devastated me. It was the one thing I wanted to do, I wanted to do what my dad did, and I couldn't. I even tried applying again after my treatment was complete and found to be a success, however I was still rejected.
- 20. I knew I couldn't do certain jobs from a young age. I couldn't be a paramedic, or a policeman etc. I wanted to be in a job that made me feel that I had an impact on people, but with all the restrictions this illness comes

with, you soon realise you have very little options available to you. I could perhaps be a factory worker, but that was never enough for me, because I know I am better than that. It just takes everything away from me; it brings on a burden and rips away all my aspirations. I know deep down I could do better, but I was ripped away from any opportunity.

21. It's been really difficult to keep a job because of the difficulties of li	ving with
hepatitis C and going through the treatment process. I was a train co	onductor
for GRO-B I started with them on the GRO-B	I started
working there as a GRO-B and was promoted to a guard in 2010.	was with
GRO-B for about 10 years and when I was physically fit ev	verything
went swimmingly well. In the last 5 years, my health started deterio	rating as
the treatment process went on. I wasn't myself and felt awful taking	g time off
from work to undergo treatment.	

- 22. The treatment really affected my sleep and I wasn't feeling myself. I would sleep through 3 alarms which made it impossible to get to work on time. I had no energy in me even when I was at work. I felt the company tried to get rid of me many times, but they had to be very careful in how they handle me as liver cirrhosis comes under the Disability Act. Regardless, they have disciplined me because I have been ill and they claim it's costing them too much. For the last year, it's been extremely difficult, as I felt exhausted before, during and after work.
- 23.I was scared of losing my job because I was ill all the time. In the end, I was dismissed, but for another reason. The incident was just a massive convenience for them to get rid of me. However my illness and taking so much time off had fundamentally affected my job.
- 24.I have suffered from depression and experience mood swings. One time I feel fine and the next minute I can just snap at the children or my wife for no reason. I still feel like this, and due to my lack of energy, I think it also has

- to do with the amount of drugs that have been put into me. It's a bit like chemotherapy, but the only difference is you don't lose your hair.
- 25. Counselling was offered to me throughout my life. Every time I started treatment I was always told I could speak to someone, but I have just never done it.
- 26.I have been to dark places, but I have always been able to get myself out. I want to be able to live. I feel like I missed out on my childhood and a lot of things I wanted to do, but I continue to fight it and not let what happened to me become who I am. I am better than that. My children keep me going together with my wife and family.

Section 6. Treatment/Care/Support

- 27. I believe I had undergone about 10 treatments. One of them was a study because I was travelling to Birmingham. I was taken to A&E when I suffered constant pain on the right hand side of my stomach and I was given morphine, because the hospital couldn't tell why I was getting this pain besides the Hepatitis C.
- 28. As a child I had to take a lot of days off school. I remember the local nurse came to my home every week and took my urine sample to check for blood. I remember I sat on a certain chair and she would inject me at home. I can't remember how ill I was at the time. I had that done once a week. I was no older than 11 years old.
- 29. The treatments in my adult life have been the worst. The first one was in a tablet form. I'm not sure what it was called but I believe it was called Ribavirin. It made me so ill, not to the extent that other people were, but I had suffered fever and anxiety from knowing I was going to be sick as a result of the tablets. The pain in my leg got worse and being in bed did not help. I was not eating and lost a lot of weight. As result of this I was off work

for 3 months. For each treatment I had to have time off work, following which I had to undergo a 'back to work' interview and medicals.

- 30. The worst thing about these treatments is just as you get back to feeling normal, you are injected again, I was in bed for about 5 months continuously. My blood count was hundreds of millions, and it needed to be cut down to below a million. Mine never went the below million mark, thus this treatment had failed.
- 31. The second treatment lasted 6 months and it was the same as the interferon but had a new drug. I have taken so many treatments over my lifetime, I was sceptical and convinced this wouldn't work. In fact I almost didn't want to believe it would work, as I was scared of facing the disappointment again. I have sat down so many times and argued with the injection pen saying 'I don't want to take you.' It was truly a horrendous experience. The hardest thing about this treatment was going on the interferon having it constantly put into my body.
- 32. The third treatment was successful in 2015 and lasted for 12 weeks. It was a great feeling to know that it could work but the thought of having to go through taking more injections again was really distressing. I also didn't want to get my hopes up, only to be disappointed should it not work again. The treatment was the same as the other two, but with different drugs added. The hepatitis C may have gone, however I still have liver cirrhosis and have a higher chance of liver cancer than the average person.
- 33.I didn't have any difficulties getting the treatments, but it was just waiting to get the treatments. I believe it was easier for me to get access to the treatments as I was a young fit child and they probably felt the medication would work better on me, so as a result I underwent all these treatments.
- 34. I feel pain in the right hand side of the stomach and rib area permanently. I still feel pain and now I know what it is from. I also suffer from short term

memory loss, which is a massive problem. I can put something in a room and completely forget where I'd put it. In addition I suffer from severe migraines, depression and mood swings.

35. As well as the impact this whole thing has had on me, people don't realise how much of a burden this has had on my family. My children missed out on a dad because I was always too ill.

Section 7. Financial Assistance

- 36. When I was about 16, I found out that I was entitled to the Skipton Fund payment. I believe my doctor had informed my solicitor and I found out about the Skipton Fund. I submitted an application and it was accepted so fast, which is what makes me more suspicious that there was more than a transfusion.
- 37. The award was paid in two instalments. The first instalment of £20,000 was paid in 2000, and the second of £50,000 was paid in 2013. The process was quite distressing, as you had to prove certain things to receive payments. Firstly, that you had Hepatitis C from plasma or blood transfusions, and secondly that you are close to dying and have liver cirrhosis (so the threshold was quite high).
- 38.I also receive monthly payments of £1,500 from 2012 from Skipton and Caxton, which I believe is now given by the EIBBS.
- 39. Receiving financial support has not been easy. I felt at times I had to prove I was dying and that I had to beg. The process in itself was quick enough, but it would have been better to give me a lump sum so I can leave it for my kids and wife. If something does happen to me, they can cover my funeral costs, but I am not sure if they can give anything more.

Section 8. Other Issues

- 40. I have three active court cases ongoing. Two of them are linked to Hepatitis C. The first one comes under discrimination; we are arguing that people with Hepatitis C and HIV get more than people with just hepatitis C. I believe it has been to court for a hearing date and I am being supported by Leigh Day. The second case concerns compensation. I was asked by the Contaminated blood Community to join a case against the NHS and the government. I am also pursuing an action against my former employer for unfair dismissal in which I am supported by the GRO-C
- 41. We did have full medical records but they have been lost. Leigh Day have applied for them for the ongoing court case and I know there is definitely evidence there as Skipton would have checked before releasing awards.

Statement of Truth

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

Signed GRO-B

Dated O6/2/19