Witness Name: GRO-B
Statement No.: WITN2001001
Exhibits: 0
Dated: 19 February 2019

WITNESS STATEMENT OF GRO-B
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B. My date of birth and address are known to the Inquiry.

2. I live at home with my son who is 13 and I work full time.

Section 2: How Infected

3. On GRO-B 1991, aged 19 I had an accident playing football when I collided with the opposition goal keeper. I left the field walking, a friend convinced me

to go the GRO-B hospital which was Bradford Royal Infirmary as I was struggling to breathe. I was x-rayed but nothing was found, I took pain killers, my dad was called to collect me but before he arrived, I collapsed. There was a suggestion that there was internal damage. Investigations indicated that there was. I can recall that I signed something and I am pretty sure it was a consent form, but I cannot say what was in that document. I had three emergency operations as I had ruptured my liver. These operations took place over the course two days, on 30 and 31 January 1991. I was unconscious at the time and did not know who was there. By the time I woke up, on the 1 or 2 February 1991, my mum, my dad and my sister were there. I was told some time later that my family had been told that blood had been stock piled in expectation of there being lots of casualties from Iraq, from the first Gulf War in 1991. I was given around 60 units of blood. At that time, I did not know it was infected blood. I found out that I was carrying the hepatitis C virus 2011, I explain this below. I had been sent a letter from the LookBack Programme but I did not see it until 2011 when I requested and later received my medical records from my GP, after the diagnosis. There is a letter dated 17 August 1995 which I can make available to the Inquiry if it would be helpful, which states "*…according to available records the above patient was transfused with a presumed hepatitis C positive blood component on 30.1.91 while under the care of Mr Ausobsky at Bradford Royal Infirmary*". I do not have the batch numbers.

4. I was not infected as a result of my relationship with another person.

5. No information was given prior to the provision of blood to me about the risk of being exposed to infection. My family and I would have remembered that.

6. I have been tested for HIV, after hepatitis C which came back clear. It is just hepatitis C.

7. I found out that I was infected with hepatitis C, in around February 2011. I came home from work one day and there was a letter on the doormat. I opened it; it was from Salford Royal Hospital. It said that I had tested positive for the hepatitis C antibody. I had a further test which confirmed that it was hepatitis C and it confirmed which genotype it was.

    a. For years; from 1997, I was really sick. I visited my GP who kept putting me on antidepressants. I was engaged with GPs for a long time. I went for countless tests between 2007 and 2010. I was referred for Cognitive Behavioural Therapy (CBT) because the doctors thought I was psychosomatic. My mum heard something on Radio 4 about Anita Roddick, which prompted me to get tested. I went back to the doctor and demanded a test. I told him that I had a blood transfusion in 1991. I was sent for a test. When the test results came back from the hospital, I got a letter directly from the hospital which confirmed that I had the virus. Once confirmed in the letter, I was pretty sure that I had contracted it from the blood transfusion(s) I have been given during my operations in 1991. I requested my medical records from my GP. These medical records confirmed that I had the infection. No information was provided by a medic initially. I just had the letter from Salford Royal Infirmary telling me I had tested positive for the antibody, and that was it.

    b. Eventually I was given adequate information to help me understand and manage the infection. This was only when I was referred back to the hospital. By this stage I had done lots of research to understand what it meant and knew what I was dealing with.

    c. It has transpired; following my request for my records in around March

2011, and post diagnosis, that the LookBack programme had attempted to get in touch with me in 1995 and 1996. It appears from my records that they wrote to me on three occasions once via my GP dated 17 August 1995, once directly to me dated 3 October 1995 and again directly to me dated 15 January 1996. The two letters to me were to two different addresses. None of these letters reached me including the one that was written to my GP. The letter to the GP dated 17 August 1995 stated *"...according to available records the above patient was transfused with a presumed hepatitis C positive blood component on 30.1.91 while under the care of Mr Ausobsky at Bradford Royal Infirmary"*. I was a student at the time and was moving around a lot and moved to Manchester on 6 January 1996. As I was on asthma medication I would have registered promptly with the GP in Manchester. I have no idea why previous or subsequent GPs did not communicate this information to me. I understand that the GP received another letter dated 12 February 1996 which stated that two attempts were made to contact me and to refer me for counselling and since they had heard nothing they would close my file. I believe that this happened. No further attempts were made to trace me. The action of closing the file like that could easily have led to my death. The whole time this information was on my file, it was obvious what the problem was, I was attending my GP because I was sick and this information did not reach me. The information on the file would have answered all my questions and would have stopped me taking antidepressants for 10 years. I was experiencing classic hepatitis C symptoms. No-one told me. The records can be sent to the Inquiry should it be helpful.

d. I was told by letter. It was extremely destressing to learn about it that way. I had been living at home with my young son at the time. On that particular day he was with his mum. I was at home alone. It was dark outside. I had nowhere to go. I did not know what the hepatitis C actually meant, I did not know who to go to, who to speak to. To get a letter through the door like that was terribly destressing. I was so upset that I could not speak to anyone, I could not explain to my family what had happened. I was in disbelief. When I eventually found out that attempts were made to contact me in 1995, I was absolutely furious; very angry. It is now very difficult for me to engage effectively with healthcare providers in a healthy way and it has instilled in me an inherent distrust of the healthcare system. The cumulative effect of this is I still struggle.

e. Once the letter came through I researched hepatitis C myself. I found a support group and people to talk to on the internet. I knew what I was dealing with. I was told around one month later by hospital staff what the prognosis was and what the risks of others being infected were. It is difficult for me to isolate what I was told, from what I already knew from my own research.

Section 3: Other infections

8. I believe I have been infected with hepatitis C only.

Section 4: Consent

9. I received the blood in a life threatening scenario but I was conscious before I had the first of my three operations. I am grateful for the fact that my life was

saved. I do believe I was treated without being given adequate or full information in relation to the risk of infection of receiving blood.

10. I do not believe I was tested or treated for the purposes of research.

Section 5: Impact

11. I carried the virus and was extremely sick for around 20 years prior to finding out that I had hepatitis C.

    a. The mental and physical effects of being infected with hepatitis C are numerous.

        i. Pre-diagnosis: During that 20 year period I became more progressively unwell, but there was a real focus on the period from 2007. Life became extremely difficult; work was difficult; dealing with my little boy was really difficult. Following the operations in 1991 I recovered well from the injuries I had sustained. In 1992 or 1993 I was back playing cricket. My sport was an extremely part of my life. I was never going to make a living out of it but I was able to play cricket and football to a high club amateur standard. The infection took that away from me. By 1995 or 1996 I started to struggle slightly; I started to have antidepressants from 1994 or 1995, I was tired and less able to do things. The doctor just thought I was depressed. I was only in mid-twenties at this time. So for around 10 years I had fatigue; a lack of interest in socialising; lack energy to play competitive sport and that had been a very large part of my life. I also had brain fog but I was unable to articulate that at the time. I was still able to work and function. In 2007 it started to get a lot worse. Even the antidepressants were not working any more. I was struggling to get enough sleep; I remember needing to sleep during the day for an hour or two at around 4.00pm. I recall my partner saying to me at the time, that I was a different person when I was able to have a sleep after work. I had to balance my daytime sleeping around childcare and work. I started to worry how much longer I could work. In 2008, 2009 and 2010 I visited the GPs every month. I had brain fog, sore throats, muscle and head aches, and fatigue. I felt like I was 70 years old. I was still trying to cycle but I was going slower, slower and slower. I kept going to the doctor. I was sent for all manner of tests none of which were for hepatitis C. I understand my liver function tests at the time were reasonable. I was finally diagnosed in 2011. Thinking about the mental impact during this period of time, it is difficult for me to explain. I was seeking help and was given antidepressants and told I was possibly psychosomatic and referred for Cognitive Behavioural Therapy. I think it likely that there was an impact but because I did not know about the infection I was unable to attribute it to anything. I expect I quietly acquiesced to what the GP was saying. It is hard for me to distinguish between the physical impact and the mental impact. I was too tired to go out and so did not want to but intertwined in this was the lack of interest in going out. So the lack of interest could be attributed to the mental impact of the virus and infection.

ii. Post-diagnosis: I continued to get worse until the treatment began in November 2011. I cleared the virus and improved for around two or three years from around 2011 to 2014. I started to feel ill again in 2014; I started to get worse again. I have been treated again recently. While I am technically clear of the virus, I am definitely not well. I am still very tired and eligible for the special category mechanism. I am constantly trying to manage when I am able to function properly, which is usually just in the morning time. From around 3.00pm in the afternoon it is like I am drunk. There are two physical impacts for me, one being the effect of the interferon and the other being the effect of the virus. I still have fatigue and tiredness; the same symptoms as I had in 2011 but perhaps not as severe. What has happened since 2011 has affected my mental health. The mental impact stems from the lack of trust in healthcare. I do not want to go to any doctor for anything. I panic about my health, to a disproportionate degree compared to how I used to be. So I panic myself about my health but will not go to the doctors. This is why the support groups are so important. I tend to lean on them a lot to help me through. Key thing for me is that the doctor at the time in 2011 was sending me for CBT as he felt there may be psychosomatic problems. I could not understand it and it made me distrust my own centre of gravity; it affected my confidence and has impacted me in social situations. I used to be really sociable; the life and soul of the party; being sociable was a natural part of playing competitive sport and something that I really enjoyed. I do not want to go to the doctors again, I do not want to socialise. I am quite happy to stay at home with my son and play games with him. When I found out, I had to contact previous partners to advise them which was extremely difficult as some of them were married with children. This was horrible. There was also a risk to my child. My son's mother was tested and she was clear of the virus so we knew that he was fine. This resulted in a total mistrust of everything. It has changed my life and in particular in relation to what I want to do and how I want to do it.

b. I have been having lots of complications with my teeth. I do not know if the problems are related to the interferon or the infection, but they are significant. They are falling out, rotting very quickly. The rate of deterioration has slowed down. I have also lost a lot of hair when this is not a prevalent thing in my family.

c. I was given a six month course of interferon and ribavirin in November 2011, it lasted until May 2012. This cleared the virus, to the extent that my viral count is now zero.

d. Once I was diagnosed, there was a slight delay in that the treatment did not begin until November which was eight months after my diagnosis. This delay occurred because I was under the care of a consultant at Salford Royal who could not treat me at that hospital as there was no treatment centre there. I had to be re-referred to North Manchester General Hospital for the treatment to take place. Other than that there were no difficulties or obstacles in obtaining the treatment.

e. I think I received the correct treatments for me. I was not aware of there being anything else available. Had I been diagnosed much sooner I am not sure what treatment I could or would have had.

f. It is difficult to separate the effects of the hepatitis and the treatment. I completed a 24 week course of the treatment. I know I had to sleep more; during the day I would sleep at lunch time for an hour and a half and I would go to bed earlier than normal, usually at around 8.00pm and I would have 12 hours sleep. I would get breathless after walking only 100 yards, or on any slight incline. I remember feeling upset during the treatment. I became very introverted and protective of myself; like a recluse. I did not want to interact with anyone, or be intimate with my partner. Fortunately, she was very understanding. I turned 40 on treatment. Turning 40 is significant milestone in one's life and I knew people would want to celebrate with me, but I did not want to. I just wanted to stay in my house and get on with the treatment. I had no desire to engage socially. I think that I was suffering from depression. I was able to work, but only just and only because I have complete control over my work, so I could decide what tasks I did and when. I was in a warm environment, I could get into work quite easily; it was a 10 minute drive. It was easy to get to and to get home. I was very fortunate with that.

g. No, I do not think that my infected status has impacted upon my treatment, medical and/or dental care for any other conditions.

12. The whole thing has changed me as a person; I used to be quite happy-go-lucky, active and gregarious.

a. I have no doubt that a number of relationships in my 20s and 30s were significantly impacted by my mood and the tiredness. A classic thing was that on a Friday night I never wanted to go out because I was so ridiculously tired. This was not well received. I did not have the mental energy to sort things. I just could not be bothered. As I did not know what was causing it, I was unable to discuss it with a partner and so I just appeared to be moody or grumpy or suffering from mood swings. So there were two or three relationships that ended as a result. I was with my current partner when I was diagnosed, the first thing I had to do was tell her and she obviously had to get tested. We both have children to other partners and we do not live together. When I was diagnosed my general mood became understandable to my partner and to me. It gave us both a framework to rationalise what was happening. I think knowing about it, helped our relationship. I was infected with the best genotype for clearance prospects so that gave me confidence that I would not "kick the bucket".

b. My mum lived in Ghana, my father in Yorkshire and my sister in London with her family. My family were obviously very worried about me. My mum was particularly worried as she would call all the time especially when I was on the treatment, but I could not speak to her. My mum's worrying increased which in turn made me more stressed.

c. Socially I withdrew. The whole way through I have become less and less sociable. I have a small number of close friends that I have had for a long time and who live in different parts of the country.

13. I do not believe there was an impact on me or on my family of the stigma associated with my hepatitis C.

14. I have been completely and utterly tied to my job because I know that it would not be in my interests to move from where I am both geographically and

professionally; I have the perfect job to help me manage the effects of the impact on me. I have been with the same organisation for 15 years and professionally I am as senior as I can be. Everyone at work knows that I have the infection and they understand and are flexible around that with me. I believe that I would have been promoted had I been somewhere else. If I had not had this condition I would have moved to seek promotion but I have had to compromise on that.

15. There has been an impact on my son and on my partner.

  a. There has an impact on my son:

    i. In around 2008 we went camping but after that I deteriorated physically so we have not been able to go camping again. My son asked me frequently when we could do it again, which we both found difficult.

    ii. There have been other things that I have not been able to do with him because I am too sick. The hepatitis C has dictated to us what holidays we can have together.

    iii. My son also saw me very sick when he was very little, only four or five years old. He had a really good book which helped me explain to him how I was feeling and what was happening, so he understood.

    iv. I was not enthusiastic about having lots of children over for play dates so I encouraged those to happen away from home. I am not sure he realised but I did worry about it. I had to do it because I felt like I could not cope.

b. The impact on my partner:

   i. When I have my time with my partner; which is every other week because I spend the other week with my son, I have to go to bed early (as I usually do) because I am too tired to stay up. I also struggle to concentrate on our conversations and interaction with one another. Our efforts are focussed on doing things at the weekend instead but even then, our hours of quality time are limited. The infection has limited the quality time we can spend together.

Section 6: Treatment/Care/Su6pport

16. I do not believe that I have had difficulties obtaining treatment. The financial support has improved in the last year or two to the extent that I attribute; to an extent, the EIBSS money I get to the financial value of the loss of opportunity. I find it difficult to accept that although I have had this virus since 1991 the regular payments for Stage One only commenced two years ago. I have been struggling and have had a loss of earnings for years but nothing to compensate for that.

17. Other than what has been offered through the Inquiry, counselling and psychological support has not been made available to me. I consider that this has been wholly inadequate. The biggest help and support that I have had has been through the self-organised Facebook groups that I have been part of. I

attended a meeting in Manchester last year and it was the first time I had ever sat in a room and listened to other people who had been infected. These social media groups have been invaluable to me. They have helped with even the smallest things; they helped to explain certain things to me.

Section 7: Financial Assistance

18. I have received financial support from the Skipton Fund and EIBSS.

    a. I knew that financial assistance was available to me from the point in time that I was diagnosed; I worked in the benefits system so I knew what would be available.

    b. I received the Skipton Fund one off £20,000 payment in 2011. In 2017 I received the Stage One regular annual payments of £4,000. From April 2018 I applied for the Stage One Special Category Mechanism (SCM), and this was awarded. I receive £18,500 per year. I also receive a discretionary top-up payment which is income related; I received another £3,000 for that. This is means tested.

    c. I completed the application myself and took the application form to my GP for him to attest to what I said in the application. The consultant had previously written a letter to say that my condition was highly likely to be as a result of the hepatitis C or the treatment for it.

    d. On the Skipton Fund payment, I recall that I did sign something and was left with the impression that by signing whatever it that I was not able to take further action, even though they made it clear they were not admitting liability.

e. I do not understand why there is such variance in the payments; they seem to depend on where you were infected. The administration and the levels of error I have encountered through EIBSS are too high given the level of simplicity of the scheme. EIBSS have focus groups; these are supposed to listen to and address valid difficulties and concerns that participants and applicants to the scheme have. My experience of these groups has been that they are completely ineffective. It appears as though the scheme wants to show that it is listening to people but in my experience any recommendations that are made are not even <u>considered</u>. The standard approach is "*we are not changing the scheme*". I can provide certain examples of the ways in which the scheme operates that are completely and utterly ludicrous. One example is that they assume that the impacted person has at their complete disposal the income of every adult in their <u>home</u>. This scheme includes an elderly parent and/ or an adult child and assumes as a default position that you as an impacted person have complete control over the whole amount of their income. This does not happen for benefits purposes. This elderly parent or adult child would not be treated in the same way for benefits purposes. I have been working in the benefits field for 22 years and I find this totally unacceptable. This is just one example of many that I could provide. I have a spreadsheet of worked examples and have letters which support what I have stated above if the Inquiry would like to see them.

Section 8: Other Issues

19. Clarity about who knew what and when in relation to contamination of blood and for me the when part is critically important because I was transfused in 1991.

20. I am hoping for truth, for everyone but also clarity and consistency in relation to the financial arrangements. The different UK countries; for example Wales, are dealing with the problem entirely differently in terms of financial support. This is unfair especially when one considers that we were all treated by the one NHS.

21. The service that I have received from the GP practices has been deplorable. The GP practice I am most aggrieved about is the practice I was with from 2003 to 2018. The practice name is GRO-B and it has two doctors the significant one is Dr GRO-B I moved practices because the relationship had broken down, this stemmed from the fact that Dr GRO-B missed the letter in my notes that contained my diagnosis for years, despite me visiting him with major symptoms and on a consistent basis. It would have taken less than ten minutes of his time to find the root cause of my health problems. From the post-treatment phase 2012 to 2018, he never accepted that my symptoms were linked in any way to the hepatitis C, those included chronic fatigue. Towards the end of my time under his care, I told him I was deeply unhappy with the care he had afforded me and that I was going to complain. He said "*complain away, as there is no way you can touch me*". His mobile phone rang while I was in his office and he took the call. This took place on 5 January 2018 at 16:35. I have photographic evidence. I sent a message to my friend who runs a charity called Healthwatch to complain about what he did. It was only when I went to see the consultants through my new practice that it was accepted that

these symptoms were likely to be related, and that there was nothing further that they could do, but I was happy with this. My treatment now is first class. I stayed with them for so long because I did not have the strength to move on.

Statement of Truth

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

Signed: GRO-B

Full Name: GRO-B

Date: ~~19.02.72~~ 19.02.19