Witness Name: GRO-B
Statement No.: WITN1919
Exhibits: 0
Dated: 23 July 2019

INFECTED BLOOD INQUIRY
WITNESS STATEMENT OF GRO-B

Section 1: Introduction

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

2. I have been married to my wife since 1992. We have two daughters, one 26 and one 24.

Section 2: How Infected

3. On March 16 1985, I was involved in a road traffic accident where I suffered multiple fractures to my right leg. I was unconscious. I was taken by ambulance and was given a blood transfusion as I had lost so much blood. My tibia was pinned and plated and I was placed in traction for seven weeks so that my femur could be pulled back far enough for a metal rod to be inserted and pinned. I had several transfusions whilst in traction. At the point at which I had my femur operation, I had a further transfusion. I do not know how many

units were transfused then. I had a further three surgical procedures over the following ten years to remove plates, pins and screws and to correct problems with the toes on my right leg.

6. I was diagnosed with hepatitis C in 2007. I was infected with hepatitis C as a result of receiving the blood transfusion.

Section 3: Other infections

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

Section 4: Consent

9. I was unconscious at the time that I arrived at the hospital after the road traffic accident and so not able to consent to the transfusion.

Section 5: Impact

10. The impact of this on me and my life has been horrific. As soon as I was diagnosed it was like a downward spiral and affected everything. Everything. Work, relationships, social life. This virus knows no boundaries.

11. From around 2006, I started feeling tired most of the time and I realised I was suffering from a major loss of energy. I had always been very physically fit and active, and had trained in martial arts to the point where I was competing in national competitions. I was doing well and I think that the endorphins helped to balance how negatively I had started to feel. Initially, I was not really aware of how bad I really was but there had started to take place a very slow deterioration in my health.

12. I remember starting to get colds and flu all the time. I remember feeling like I had flu every day. This flu like feeling made me feel tired and sick and caused me to lose my appetite and I started suffering from headaches. I did not realise how bad these issues actually were until after I was successfully treated for and cleared the hepatitis C virus.

13. When the symptoms started to kick in, I recall starting to feel down and low a lot of the time and to feel depressed; I had never experienced these feelings before. I gradually started to suffer from an inability to function in normal way; I noticed I was unable to do the usual normal things that I had taken for granted such as, talking to people in a relaxed way and feeling happy and staying calm when things went wrong.

14. My personality began to change as a result of being in constant physical discomfort, which I believe led to me to develop a degree of mental weakness that I did not have before. I was offered antidepressants but I did not take them. During this time I started losing sleep and to sweat at night, which eventually became so bad that my bedding started to get soaked with sweat. My joints and muscles were aching all the time and my muscles started to become tense. The joint pain and muscle pain has gradually improved after I cleared the virus.

15. I also started to feel cold all of the time and so much so that it became debilitating in winter months. I still feel cold now; even though my treatment has been successful, but the cold feeling is nowhere near as bad as it used to be. I sometimes struggle to get warm, which causes me to feel unwell and in discomfort. When this happens, I am unable to do normal things like my volunteering work and from being able to engage properly in social activity.

16. It is like I have an inability to tolerate any discomfort now because my body has been through so much. It makes situations intolerable as I just want to get home and into the warmth and comfort. This is very unlike me as I used to like to exercise in extremely cold weather; I found it refreshing and invigorating.

17. Since around 2008 I remember I started to suffer with my short-term memory; I developed concentration problems and I found completing complex mental tasks such as completing my financial returns for work extremely challenging. From around 2013 I started to get 'brain fog'. I knew it to be brain fog because my research into the effects of the infection had introduced me to the term. I

know that I was starting to forget things for example, I started to forget why I had walked into a room, what I had said to someone earlier in the day and getting confused when I asked people about things they had already told me. The memory loss issues made this period of time extremely worrying for me and for the first time I felt like I could not do my job properly and that I was possibly putting people's safety at risk. From 2006 onwards I started losing weight for no real reason; I went from around 14 stones to 10.5 stones when I was at my most ill. My energy levels dropped and my appetite became extremely poor.

18. In 2014 I developed full cirrhosis of the liver and later; in mid-2015 I went on to develop hepatocellular carcinoma in the right lobe of my liver. This cancerous tumour was so close to an artery my surgeon said he would have to remove the whole of my right lobe. After reviewing CT and MRI scans my surgeon explained that my left lobe was not big enough at that time to sustain life so he planned to perform an embolism of the liver to kill the blood supply to the right lobe. This was a most painful operation, which involved a 3-hour procedure whilst I was awake and under a local anaesthetic. The anaesthetic did not kill all the pain. The surgeon preferred to conduct the surgery on local anaesthetic.

19. In recent years I have suffered with many urinary tract infections (UTIs). Since my liver resection, which included removal of my gall bladder, I have problems and difficulties with digestion. I constantly suffer from difficulty to urinate and have been under the care of a Urinary Consultant since 2007.

20. Since my liver resection I suffer from fluid running into my right testicle, which becomes swollen and painful when I do a lot of walking or any running. The resection has also caused me to have an enlarged spleen. This affects my platelet levels and as a result I suffer with anaemia and from bruising, mainly on my hands. This will never improve. However, when I was most sick and ill with the cancer at pre and post surgery, I regularly had bruising on many parts of my body, even around my genitals with any slight knock causing bruising. The bruising felt like it was happening on every part of my body and was quite scary

to live through. The bruising issues have now got better and are rare now but it has been extremely worrying, humiliating and embarrassing to go through. However, I still suffer with muscular pains around my abdomen due to the procedures.

21. I was given Interferon and Ribavirin for six months in 2007, which failed to clear the hepatitis C. I then underwent liver resection surgery, which removed the cancerous tumour. Finally in 2016 I was given the new direct-acting, non-aggressive drug Dakllinza/Daclatasvir along with Ribavirin to treat my Genotype 3 Hep C. I had the dual treatment as I had previously failed the standard Interferon and Ribavirin treatment.

22. After the first treatment failed in 2007, I decided to get myself as healthy as I could and to wait for my chance to get the new treatments that were being talked about and tested at that time. I had this discussion with my consultant who told me that the new treatments were not guaranteed and that I needed to be aware of setbacks because often they failed at the final stages of testing. I asked my Consultant Hepatologist for the Daclatsvir in 2015. He told me that it would not be available to me because it was so expensive and was only going to be given to first 500 most sick people throughout the UK and that the majority was transplant patients.

23. I appealed to a senior person within the NHS who backed the decision that had been made by the hepatology department. At this stage I became very worried as I knew that I was probably only likely to live another year if I did not get treated and clear the virus. I went to my local MP **GRO-B** who was sympathetic in words but did not take any action other than repeat current NHS guidance on Hep C treatment options. I then went to NICE; who said that NHS should give me the new drugs as it was more cost effective to have the treatment than to not have it and then have the cost of the resulting sickness from not having the treatment. NICE said that they should be giving me the drug and within 3 months.

24. I then went to the Hepatitis C Trust for help and they supported me and

represented me in challenging the NHS for the new treatment. Finally, in 2016 the NHS agreed to treat me and I was given the treatment, which I know for sure has saved my life. I only knew about the drug because I had done my own research and kept myself aware of what was going on.

25. I believe I should not have had to fight for the new direct acting drugs and that I should have been offered them without a fight straight after my liver resection. Had I not received this treatment I am 100 percent that sure I would not be here today. The hepatitis C virus would have eaten away at the remaining left lobe of my liver and I would have developed another cancerous tumour and would have lost my life. The remaining part of my liver was so small that it was only just helping me to sustain my life.

26. When I started on the Interferon and Ribavirin treatment in 2007 I was 13 stones and when I finished I was 10.5 stones; you could see my bones all over my body including my scull, my ribs were showing and I had yellow and blood shot eyes.

27. I suffered severe mental health problems where I regularly lost control of my emotions; I felt extreme anger, and I became aggressive. The illness prevented me from being able to communicate properly with my friends, family and others. I had severe hair loss; I was sick all the time and suffered with extreme bouts of insomnia. I suffered with social and family problems due to extreme mental and psychological weakness brought on by this treatment regime. This treatment had such a detrimental effect on me that I started losing my confidence, self-esteem and self-worth.

28. I started letting things get to me such as getting into arguments with people, getting into road rage and falling out with workmates, friends and family over trivial things. This also affected my home life where I became agitated with my daughters and wife. After my liver resection procedure, I was unable to walk, for about six weeks. When I was able to walk I was in a lot of discomfort. When I did manage to move around, if I coughed or sneezed I got shooting pains in my abdomen. It was like that for around six months. I had pain in my stomach and

suffered digestion problems for around 18 months, the pains are still there but not as bad as they were. I am still under the care of the Surgical Liver Team and also under the care of Hepatology Team at GRO-B. I see them both every six months. There were no side effects with the direct acting drug.

29. Every time I have had any form of medical treatment or care including dental care, I have had to declare my hepatitis C status. I do feel that over the years, because of this, I have been made to feel like I have a 'dirty disease' associated with homeless people and injecting drug users.

30. Over the last 10 years I gradually lost the ability to do physical activity, I suffered a major loss of strength. I was unable to socialise properly and struggled in my domestic, social and work interactions with others. This was the beginning of deteriorating mental health, which was mainly a deeply depressed feeling. I hand major problems with my friendship with others, which caused a decline in my family relationships. I just did not feel happy, healthy or sociable. I have lost many good friends, jobs and suffered family break ups.

31. A big part of my life had always been about taking part in regular fitness/weight training, playing football and practicing martial arts. Up until 2005 I was a regular at martial arts and GRO-B I competed in national tournaments across the UK. I also played football and did weights three times per week. However, I now understand that as the hepatitis C got worse I had to eventually give up my martial arts and I was unable to train as much when I started suffering with the physical and mental issues. I had to stop playing football in 2012 as I was always 'losing my head' and getting into raging rows with my friends, fellow teammates and opposing players.

32. During the time of my first treatment experience with Interferon and Ribavirin I had great difficulties with my family, especially with my youngest daughter who was badly affected by my physical and mental state. She saw her father who was a big strong confident man become a feeble, skeleton-like mess. I believe

her education suffered because she slipped from being on The Gifted and Talented Register and a potential A -Star student at school, to a depressed and moody girl who was showing signs of extremely challenging behaviour. These issues have had a detrimental effect on her and on her transition to adulthood and have severely affected her life chances.

33. The hepatitis C has also affected my private life significantly; it caused me to have marital problems and resulted in our relationship to be so strained to a point where my wife walked out on me. My personality changed when I became most ill. I often got into arguments and became offended by small things with my friends. I believe I have lost many friends due to my mental state during the worst days of my illness. This has made my social life and long-term friendships suffer.

34. I find this question about stigma very hard to answer. It is very hard for me to be sure of being treated because of a stigma. Nothing major sticks out to me, but I do think that I have suffered from the stigma around the virus. I hate filling out the forms that require me to say that I have hepatitis C and when the nurses and doctors put gloves on and when I see the skull sign around the hospital where I am which makes me feel like I am the 'dirty patient'.

35. There have been educational, work and financial effects of this. When I finished university in GRO-B I was told by the University that I should complete a Master's Degree. I did not feel well enough to cope with it. I did not feel focused and determined enough to deal with something like this. I have had many difficulties at work such as becoming stressed in situations that I used to always be able manage quite easily. I started getting into arguments with others and unable to communicate effectively. I was dealing with things quite aggressively which was completely out of character for me. I was dealing with things too emotionally; my emotions were overriding everything, all of my decisions. This resulted in some grievances and difficulties with getting along with colleagues.

36. I always had a good work record and was quite a popular person and easy to get on with but when I started suffering with the hepatitis C and all of its associated side effects, I got into many conflict situations. In late 2012 I started suffering from encephalopathy where I started losing my memory at work and in 2013 I was unable to continue with some of my roles of responsibility. It was clear that my illness was affecting me so badly that my decision-making made some situations to be potentially harmful to other peoples' safety. I eventually had to step down from my management role and in 2015 was retired on ill health.

37. I believe my career would have gone far, and much further than it had done when I retired from work on the grounds of ill health. I was only 51 years old when I did retire. I would have achieved much more at work professionally and been better off financially had I not been infected with Hep C. My work was vocational and very important to me. I was passionate about helping others to make positive changes in their lives. I derived a lot of satisfaction from my work. I am sure that had my career not ended early I would have been promoted and received better pay as a result; but, the Hep C hindered me and eventually it ended my career.

38. This infection has had a major negative impact on my family. Whilst I was living with the hepatitis C disease it affected my youngest daughter so much that after my surgery and when I was the most sick she smashed her bedroom up and the bathroom, the stairwell and attacked me with a knife in the house. She later dropped out of University and ran away and we did not know where she was for six months. She returned home and continued being aggressive and threatening towards me.

39. We managed to access help from GRO-B Hospital Psychological Team. This team helped me to live through these problems and find ways to keep myself well. During this time both my wife and my youngest daughter left home and moved into a separate flat. These issues continued after she came back

home and only in the last six months things have started to gradually improve. However, my youngest daughter is now unemployed and has some social difficulties and she suffers from mild mental health issues. She is currently seeing a counsellor and is seeking employment. I believe her mental health problems are as a direct result of living with my illness.

40. My wife has greatly suffered from living with me through this illness and at the highest point of my illness she left me. My oldest daughter stayed with me and supported me and cared for me through those difficult days.

Section 6: Treatment/Care/Support

41. Yes I have faced difficulties and obstacles in obtaining treatment, care and support in consequence of being infected with hepatitis C. As I indicated above, I was refused and had to fight very hard to access the new direct acting drugs in 2015, which I knew would and ultimately did save my life. Since having the treatment and clearing the disease, I feel my life has got much better and I sometimes get a strong feeling of wellbeing. Maybe I feel a little more like I did before I was infected with Hep C or just not so much in discomfort anymore.

42. I received counselling sessions with a local counsellor and 40 massage therapy sessions through Caxton Fund. My family has received counselling via GRO-B GRO-B Psychological Team. The local counselling sessions did not help me and eventually made me worse as the counsellor's skills were so poor (I believe partly due to her lack of knowledge of the disease); I had to stop this counselling early. This negative counselling experience highlighted that a specialist counsellor was needed but none were made available through the Caxton Fund.

43. However, the massage therapy was useful helping me to improve my sleep and release some of the tension in my muscles. The family counselling we received at GRO-B Hospital was extremely beneficial. It was vital in helping me to

maintain my sanity during the difficult family situations we experienced. It helped me to find ways to cope and think differently about how to deal with conflicts. The counselling also helped me to live through the most debilitating part of the illness. This family counselling also helped.

Section 7: Financial Assistance

44. I have received financial assistance from Caxton, Skipton and EIBSS Funds. In 2007 my GRO-B informed me about the Skipton Fund. I received £20,000 from the Skipton Fund in 2007. In 2015, following a diagnosis of cirrhosis I received £50,000 from the Skipton Fund. I received regular monthly payments from Skipton and have done since 2015. These payments amount to approximately £18,000 per year.

45. I had to apply to Skipton Fund for the £20,000 ex gratia payment and the £50,000 when I was diagnosed with cirrhosis. I also applied for the regular monthly payments for being cirrhotic.

46. The Funds I have accessed have been helpful for me to manage better living with my illness. The financial support has helped lessen the financial demands of day-to-day living; but, the money does not in any way compensate me for the damage and loss the hepatitis C infection has caused, on me and my family, emotionally, physically, mentally, financially, and socially.

Section 8: Other Issues

47. I have no other evidence to offer which could be of assistance to the Inquiry's investigation.

48. Similarly, I have no further documents the might be relevant to the Inquiry's Terms of Reference.

49. I would like the Inquiry to uncover the truth of why infected blood was used to

treat people. I would like the Inquiry to reveal the identity of those responsible and hold them accountable. I would like to draw a close to this whole situation and to achieve justice for all of those who have been infected and affected.

Statement of Truth

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

Sign GRO-B

Dated : ....23 July 2019..........