



Witness Name: **GRO-B**

Statement No.: WITN2137001

Exhibits: WITN2137002 – 003

Dated: 21st March 2019

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 **GRO-B** 1957. My address is known to the inquiry. I am a full-time development officer for a national sports organisation. I intend to speak about my contraction of hepatitis C. In particular, I will talk about the nature of my illness, how the illness affected me, the treatment received and the impact it has had on me and my family.
2. I can confirm that I have appointed Thompsons Solicitors to be my legal representative. I confirm that the inquiry should send all correspondence regarding me to Thompsons.

Infected Blood Inquiry

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Section 2. How Infected

3. In May 1976, when I was 17 years of age, I was working in forestry in Dumfries and Galloway near GRO-B I was felling timber and lifting heavy logs and I injured my groin. It was quite painful and I went to see my GP. My Doctor's name was Dr GRO-B and practiced from the Doctors surgery in GRO-B She referred me to Dumfries and Galloway Royal Infirmary which has now been re-built and moved to a different location. I had an operation for a left inguinal hernia on 26th May, 1976. My surgeon was Dr McBride. I remember after the operation, Dr McBride came to my bedside and told me there had been a complication during the surgery and he had had to give me a blood transfusion. I remember my mother was at my bedside at the time. He said I had received 3 units of blood.

4. I remember the nurses on the ward were having friendly banter with me. They said 3 units of blood equated to 3 pints and that I should drink 3 pints of Guinness. They also said that I had been given blood that had been brought in from America. I distinctly remember they said as a joke I would talk like a 'Yankee Doodle Dandy' and have an American accent.

5. I was given no information or advice before the surgery about any risk of being exposed to infection through receiving a blood transfusion.

6. I believe that as a result of receiving a transfusion this blood must have been contaminated and as such I contracted hepatitis C as there are no other possible routes of infection during my life that I could have contracted such a virus. I have never injected drugs except regulated prescribed medical approved alpha interferon during my treatment regimes which happened after I was diagnosed with HCV in 1997; I have never had any tattoos or piercings; I have never received any

medical treatment abroad; I have never had any barber or shaving episodes abroad.

7. I was detained in hospital longer than usual due to my complication and the longer recovery period needed and later transferred on June 3rd 1976 to the [GRO-B] Hospital, [GRO-B] to be nearer home. I was in hospital both at Dumfries and then in the [GRO-B] [GRO-B] for a total of 12 days. My letter of discharge dated 14th June 1976 does not mention any of the above information. The handwritten note about 3 units of blood dated 25/11/02 was made by my GP Dr [GRO-B] Dobson and signed by both of us. I exhibit this letter as WITN2137002.

Discovering I was infected

8. In 1997, I was training for a triathlon. At that time I worked hard, played hard and drank hard. I began to notice I was getting a strange reaction to alcohol. I was used to matching my friends drink for drink, but I began to notice I could no longer tolerate drinking. I would get a really bad hangover and fevers the following day. I also noticed that my training was not going well. I was failing to match my times in swimming, running and cycling. I felt really fatigued. I went to my Doctors surgery and saw a Dr [GRO-D] She went through some basic tests like blood pressure etc and said I was in good physical shape and not to worry but come back if the conditions persist and I should try and not train too hard.
9. The conditions did continue, and I went back to Dr [GRO-D] several months later and she said she would give me a full medical. She took my bloods for testing. She did not say what my bloods would be tested for. A week or so later, I went back to get my results. She just said "You have hepatitis C." I was in total shock. I didn't know what it was other than it was deadly serious. She asked me if I had ever had intravenous drugs. I told her that I had never injected myself with

drugs. She kept asking me questions about drug taking and several times asked if I was sure that I had not taken any intravenous drugs. I was 100% sure I had not and did wonder why she kept asking me this question but did not think much more about it for a while.

10. Dr [GRO-D] did not give me any information about the infection to assist me to understand and manage it. She said I would have to go and see a specialist consultant and would make an appointment. This took several months before I saw a consultant and was very worried during that time that I might die as the only thing I was told was that it was a serious thing that I had contracted.

11. I do believe that once it had been discovered that people had been infected with HCV and given contaminated blood via transfusion or given blood products, they should have been given full support and up to date information. I was given no such support or counselling for many months.

12. My only view about the way in which I was told that I had hepatitis C is that the doctor just assumed I had been infected by injecting drugs. She assumed I was a drug user and had been sharing needles with other drugs users. I had no idea why she and others in the medical profession wanted to pigeon hole me as a drug user especially when I was obsessed with my sport and outdoor activity.

13. I did receive information about the risks of others being infected. This information came from Dr Peter Hayes, who is a consultant at the Royal Infirmary, Edinburgh. He is one of the top liver specialists. I had to wait 6 months before I got an appointment. At that time I had a one year old daughter, [GRO-B] and I could have passed the infection on to her. My wife and my eldest daughter, [GRO-B] (whose date of birth is [GRO-B] [GRO-B] 1989) were tested at the same time but I cannot remember exactly when this was. [GRO-B] was also tested but again I am not sure when this was. All tests were negative.

14. Dr Hayes told me the hepatitis C was a serious condition that was life threatening. He went into detail about how the infection could be passed on through blood to blood contact and possible sexual intercourse (even if a low risk). He also told me not to share a toothbrush as the infection could be passed on through that. I became very vigilant with keeping my toothbrush and personal grooming kit in a safe place and also vigilant about cuts and first aid interventions.

Section 3 Other Infections

15. I did not receive any infection other than hepatitis C as a result of being given infected blood.

Section 4. Consent

16. I know that my blood was tested for HCV without my knowledge or consent as I was never told by the doctor that I was being tested for HCV.

Section 5. Impact

17. I have always been super fit. I love outdoor activities. I regularly competed in marathons and loved mountain climbing. I have already described the circumstances in which I first began to feel unwell and the physical impact of the symptoms. Mentally, I was frustrated because I did not know what was wrong with me. Once I found out I had hepatitis C, I became very depressed as I knew I had a death sentence and worried for my family.

18. There were further medical complications and conditions that resulted from the infection. I have cirrhosis of the liver, portal hypertension, oesophageal varices and an enlarged spleen, I had to face the stigma of the disease and the psychological impact of the disease, I often

have depression thinking about what this disease will do to me and my family and how it would affect my ability to provide for my family, I have contemplated ending my life on numerous occasions. I am normally a fun-loving gregarious person who likes social interaction but this disease often made me want to lock myself away from people.

19. My family had to put up with the stigma of me having a "junkie disease". My eldest daughter **GRO-B** was at a vulnerable age and became rebellious. She was having to deal with the fact that I was seriously unwell and might die.

20. I was due to have a liver biopsy on March 12th 1997, by Dr Hayes. The biopsy was cancelled due to my liver functions tests, showing my liver to be cirrhotic. He believed the biopsy would be dangerous. I went on to have 3 lots of treatment for hepatitis C and eventually in 2016, I was told that my hepatitis C was cleared. I have been left with cirrhosis of the liver and constantly worry that this will lead to cancer. I also still have the other related complications and now have mild chronic heart disease possibly as a result of all the serious treatment drugs I have tried over the years I had set up **GRO-B** hepatitis C group in Scotland and was aware that there was a treatment available to cure hepatitis C on a 40% chance basis. I had been made aware that the side effects to this treatment were very severe and brutal. I had discussed the treatment with Dr Hayes and he did not push me to take it but eventually, in 2005/2006 my liver functions were deteriorating and Dr Hayes suggested I start the treatment.

21. I had a twelve month course of treatment consisting of alpha-interferon by way of self-injecting, 3 times a week. I also had ribavirin in tablet form. This treatment was horrific and unsuccessful.

22. On June 13th 2013, I was put on a second course of treatment. This was interferon, ribavirin and also boceprevir. After 36 weeks I was taken off this treatment because my haemoglobin was down. It was

thought that if I picked up an infection, my platelets were so low that it would kill me.

23. In 2016, I had a third lot of treatment for my hepatitis C, it was a 13 week course. I had to take harvoni tablets. This treatment was successful and my hepatitis C was cleared.

24. I did not face any difficulties or obstacles in accessing the treatments I was given.

25. I believe I was given the treatments that were available at the time for hepatitis C. I do not believe there were other treatments available that were not offered to me.

26. The mental and physical effects on me whilst taking the treatment were profound. Physically, I came out with large boils and suppurating pustules all over my body and face. My skin was very itchy all the time. I had flulike symptoms, I was shivering and cold. I had insomnia and clinical depression. I remember I was so cold I would go to bed with my clothes on. I became nauseous and couldn't eat and as a consequence I lost a lot of weight.

27. Mentally, I became very depressed. I had terrible mood swings and was anxious and irritable. My mood was so low I had suicidal thoughts. I have to say it was the worst period of my life. I would not leave the house because I was so embarrassed by my face covered in boils. My work at the time were very supportive and allowed me to work from home when I needed to.

28. My infected status did not impact upon any other medical condition. It did however affect my dental care in that I could only get an appointment at the end of the day to avoid any other patient being treated after me because of the risk of others being infected by contaminated equipment. I still believe that there is much work to be

done in analysing dental care as a possible route of infection for many people over the last few decades.

29. My contraction of hepatitis C had a huge impact on my life. I was a super fit person and enjoyed outdoor sport pursuits. I could no longer compete at a high level and this caused me to become very depressed. I was a sociable person before my diagnosis. I became very insular and withdrawn. I could no longer drink alcohol and this did affect my social life. When I was on the treatment I became a different person. I was very depressed and did not want to go out of the house. I was moody and irritable and I know I must have been a nightmare to live with. Looking back, I am surprised my marriage survived.

30. I am aware that hepatitis C is associated with HIV, intravenous drug taking and sex workers. It was assumed when I was diagnosed with hepatitis C that I took drugs intravenously. This is totally false as I have never injected any illegal substance into my body in my life.

31. I was very cautious about who I told that I was HCV positive as I believed that is what others would think of me also. I did not even tell my children for fear that they would be ostracised at school. I am a professional mountain guide, after my diagnosis I made sure that I always had an expedition doctor with me in case anyone injured themselves. I did not want to attend to them in case I passed on my hepatitis C, it was always in my mind that I was infected, and I thought about it every day of my life since I was diagnosed.

32. I had to take a lot of time off work when I was on the treatment. I was working in Edinburgh for GRO-B I had intended to go for promotions and career development within the organisation. As a result of having this life shortening illness, I did not see the point and thought about the extra stress I would have to deal with on top of having HCV.

Section 6. Treatment/Care/Support

33. I have only during my treatment been offered counselling and psychological support. I did not take up this offer as I felt so unwell. I feel that I could have been encouraged more to take up the offer of counselling and that this could have been given a higher profile. My family were never offered any counselling.

Section 7. Financial Assistance

34. I have never received any financial support from any trusts or funds. I was instrumental in setting up the Skipton fund as one of the patient representatives. This was after my approximately two year involvement in the Lord Ross expert group which was set up to look into payment and compensation schemes for those infected with HCV during NHS treatment. Lord Ross deliberated on the intensive work we produced and came up with recommendations which were then almost completely ignored by the then Health Minister Malcolm Chisholm and Scottish Government. They simply re-devolved this responsibility of financial payments back to Westminster which then went on to set up the Skipton fund. We objected to this as it was well within the devolved powers of the Scottish Government to deal with such payment schemes from a local Scottish perspective as a specific area of concern for Scottish patients who were infected via NHS procedures and to this day I am still not sure why this happened. The other recommendations were not acted upon after two years of intensive work on this expert group. I exhibit the section of the Expert Group on Financial and Other Support Report dated March 2003 containing the Group's recommendations as **WITN2137003**.

35. I did apply for financial assistance from the Skipton fund and the process was supposed to have been straightforward. I was refused financial assistance because my medical records were lost regarding

my blood transfusion in 1976. I could not prove that I had had a blood transfusion. This contradicted the agreed procedures under which the scheme was set up as it was agreed that in absence of lost or destroyed medical records the Skipton fund would trigger ex-gratia payment to patients infected with HCV via NHS procedures on the balance of probabilities which had to be supported and signed off by the patients' medical experts like doctors, physicians, specialist nurses etc.

36. A specific section was included on the application form for a signature from the medical expert that, on the balance of probabilities and in the absence of medical records that the most likely route of the patient's HCV infection was from and/or during the patient's NHS procedure(s). If this was provided by the medical expert then the ex-gratia payment should have been authorised.

37. The financial assistance available from the Skipton Fund was supposed to be non-discretionary but it turned out it was as I described above very discretionary. I did appeal and it went to a panel for consideration. I was not allowed to attend this appeal which contradicts normal appeal processes where you can usually also bring a representative to advocate on your behalf. A man by the name of Keith Foster, who was the Chief Executive at the time, was on the panel. My appeal in my absence was turned down. Keith Foster was later convicted of fraud and sent to prison for six years. He had stolen and embezzled £400,000 from the Skipton Fund which was money that was meant to pay the victims of this national scandal for the trauma and negative impact on their shortened lives. They stated on my appeal letter that it was unlikely that a medical procedure such as the one I had in 1976 would have had cause to administer a blood transfusion and as such my appeal was refused. I have therefore not received any financial assistance to date.

Section 8. Other Issues

38. For over 20 years, I have been part of many campaign and support groups that have continually lobbied for better treatment and support for infected people. I was the first non-clinician to propose and have accepted a Scottish Intercollegiate Guidelines Network (SIGN) guideline to be written on HCV for the medical profession. I also sat on this group as a patient representative. I was also part of the Penrose Inquiry as a core participant but never called to speak. I also was part of the recent Scottish Government's Financial Review group which was set up to investigate the model and procedure and payment levels for financial assistance for those infected with HCV via NHS procedures.

39. I have a lot of documentation regarding the loss of my medical records. Also, documents from the Skipton Fund regarding my appeal. I can produce these documents in evidence if required.

40. I do **NR** wish to remain anonymous in this inquiry.

Statement of Truth

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

Signed

GRO-B

Dated

25/4/19