

ANONYMOUS

Witness Name:

GRO-B

Statement No.: WITN0117/001

Exhibits: WITN0117/002-004

Dated: 16.01.2019 .

**INFECTED BLOOD INQUIRY**

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**WRITTEN STATEMENT OF**

GRO-B

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

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

**Section 1. Introduction**

1. My name is name is GRO-B My date of birth and address are known to the Inquiry. I am a retired miner. I was married in March 1958 and I have three children with my late wife.
2. I intend to speak about my infection with the Hepatitis C virus ("HCV"), which I contracted as a result of receiving a blood transfusion to treat my low blood count in 1991.
3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it has had on my life and the rest of my family.

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4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. My daughters also assist me, as sometimes my memory is not very good.
5. Whilst I am content for the Inquiry team to know my identity I have requested complete anonymity.

### Section 2. How Infected

6. I was infected with the HCV in 1991 at Barnsley Hospital, when I was given five units of blood following a visit to my local General Practitioner ("GP") Surgery, where a locum doctor, Dr Byron, examined me and referred me to the hospital. I was not feeling very well at that time and my stools had turned black.
7. I thought it was an issue with my stomach, as in 1975 I underwent two surgeries: one because I had a stomach ulcer before and the other one because I needed a vagotomy to treat a further stomach pain I was experiencing. When I went to the hospital, I was told my blood count was low and that I would need a blood transfusion; however, I was not told that there was a risk of infection.
8. I stayed in the hospital for around three days and then the doctors sent me home. Following the transfusion, my life returned to normal; I felt healthy and I did not feel any different to how I felt before. I would not have known either way that something was wrong.
9. However, I clearly remember that around 11:30am on Tuesday 10 May 1995, I received a letter from the Blood Transfusion Centre reminding me that I received blood in 1991 and that I may be at risk of contracting HIV or HCV. I immediately called my own GP, Dr Crawford, to discuss the letter and he told me that he did not have enough information to counsel me and I would have to go to the hospital to get some specific answers.

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10. Two hours after speaking with Dr Crawford, I went to see Dr Jones at Sheffield Hospital, to do some blood tests. Soon after this, I received another letter saying I had an infection, but that the doctors needed to perform some more in depth tests to provide a proper diagnosis.
11. I had to go to Nottingham Hospital to complete all the tests: they ran a very in-depth check. I went through every possible test a man could do, this included doing an ultrasound, liver biopsy, fibre biopsy and many other tests; I think the only test I did not do was a pregnancy test. They took around 13 samples of blood in total and I had to wait 14 weeks for the results.
12. On 5 September 1995, I met with a consultant, Professor Green, in one of the offices at the Royal Hallamshire Hospital ("RHH") and asked him what I had. He told me that I had HCV but that he didn't know enough about it yet as it was fairly new and they did not have any treatments for it at that moment. Professor Green asked me about how I could have contracted HCV, such as if I had used any needles or drugs, to which I replied no. He then told me that I should keep having a blood check every three months at my local GP surgery and to visit RHH for an annual check up.
13. I have been asked if I was given adequate information to understand and manage the infection, and I would have to say that when I initially found out about the HCV, I didn't receive much information from anyone; I had to find a lot of things out for myself and teach myself about HCV. Through the Professor Green's own admission, he did not know a lot about it either, so there was not much that anyone could do to help me, but I do feel like they should have been able to tell me more. I feel that the information given to me was communicated as clearly as it could have been, but I remember not understanding everything that was said; I would say that at that time they did not make it easy for me.
14. I have been asked if I was provided with information about the risks of others being infected as a result of my diagnosis and I can confirm that

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this was actually explained to me at the time. I honestly could not have asked for a better consultant to talk to about everything.

15. Professor Green also explained to me the risks related to sexual intercourse; this is when my wife and I had a conversation about our intimate relationship going forward.

### **Section 3. Other Infections**

16. To the best of my knowledge, I do not believe that as a result of being given infected blood products I have contracted any infection other than the HCV.

### **Section 4. Consent**

17. I have been asked if I believe that I have ever been treated or tested without my knowledge or consent and the answer is no, I have always consented to the tests and treatments I received.

18. To the best of my knowledge, I have not been tested for HIV or Hepatitis B; if I have been tested for these viruses, I was not told about this.

19. Whenever I went to do a test at the hospital, I would see all the samples of blood they took and if I was not sure of something or had any questions, I would always ask; RHH has been good to me.

### **Section 5. Impact**

20. The mental and physical effects that I have suffered as a result of being infected with HCV have been very difficult. One of the main things I had to deal with is lack of sleep. I have not been able to sleep properly since that fateful Tuesday morning when I received that letter through my letterbox. I am constantly tired and I still find that I have difficulty at sleeping for long periods of time.

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21. After many obstacles, I was finally able to start my treatment to cure from HCV around April 2017. The treatment was called 'Sovaldi' and involved a mix of Interferon free tablets (Sofosbuvir) and Ribavirin; luckily, there were no injections [WITN0017/002-004]. I completed the treatment in 12 weeks and although I have been completely clear from HCV since July 2017, some of the effects of the treatment still stay with me.
22. As a result of the treatment I underwent to be cleared from HCV, I have suffered both mental and physical side effects. I get really bad headaches and during the treatment I lost a lot of weight.
23. Another effect of the treatment was that and as soon as I wake up, my brain always goes into overdrive; I can never switch off. I also experienced some loose stools during the beginning of the treatment but my medication was amended as a result.
24. I have been asked if I faced any difficulties or obstacles in accessing treatments as a result of the infection. Around 2000, during one of my routine check-ups at RHH, I was offered Beta and Interferon injections to treat my HCV, however the treatment did not sit well with me. The doctors explained how the treatment worked and the side effects of having the injections and I decided not to do it. I also received some advice from the Liver Trust who said I should not do that treatment because of my previous history of stomach issues. My wife was also unwell and I wanted to be there for her as much as I could.
25. I had heard that there were alternative treatments for HCV that were not as aggressive as the Beta and Interferon injections and I consistently fought to have this treatment, but when I tried I was always denied. The doctors kept on repeating to me that I did not meet the criteria for the treatment because I was not "ill" enough and I would cost too much money.

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26. In 2016, one of the specialist doctors at RHH, Dr Cope, fought on my behalf to have the less aggressive treatment. He put forward my case and later told me that I was finally able to have the treatment I had fought so hard for and that I wanted so badly.
27. I have been asked if the infection had any impact on receiving and accessing adequate dental care. I can confirm that I never had any problems accessing adequate dental care with my HCV status.
28. My social life has changed a little bit since being infected with HCV. I did not socialise much before I got infected with HCV, but once I found out about HCV, I could no longer get up and just go on with life; I had to be more aware of where I was going and what I was doing. I did not want to make mistakes, so I always had to make sure that I was extra careful, especially with my driving; I was always pleased when I made it home safely after a drive.
29. After I was diagnosed the HCV, I found it very difficult to share the news with my family. My wife and children were understandably all devastated and it took some time for everyone to come to terms with my new health status. However, I spoke openly and honestly about HCV and I guess this helped everyone in the long run; I made sure to be as open as possible with them and not withhold anything from them.
30. I am quite open with those close to me about my HCV. My relationship with my friends has remained the same and I do not feel that anything changed once they learned about my HCV.
31. There is a definite stigma associated with HCV that my family and I had to deal with over the years. I still vividly remember that episode at Wakefield Hospital where I had to have a surgery to my hand because I was experiencing some tightness in my hands and I had carpal tunnel syndrome.

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32. I was with my daughter and I asked to one of the nurses if she had an idea of when the doctor would see me soon. She replied: "Not with what you've got, you will be last!" My daughter replied to her: "Well, why don't you tell all the ward then!" It was an awful experience. I could have walked out at that very moment; it wasn't nice at all. I feel that anytime I had to go anywhere, I would always be the last one because of my HCV; it was like I was a burden so I would have to be left until the end.
33. I also felt that the stigma negatively affected my family too. When my wife's family learnt of my HCV, they refused to speak to my family, and I and have completely distanced themselves from us; this was hard on all of us.
34. HCV never had any impact on my education or career as I completed all my education in my early years and retired from mining before being infected with HCV. HCV did not have a direct affect on me financially as I was already retired at the time of the diagnosis and I was living on my pension; however, life got harder as the years went by to, especially with the management of all my finances.

### Section 6. Treatment/Care/Support

35. At the time when I was infected with HCV my wife and I were never offered any counselling or psychological support.
36. When I later went to RHH I was told that everything was at my disposal if I needed any psychological support. Later at Sheffield Hospital I was offered counselling but I chose not to pick up their offer.

### Section 7. Financial Assistance

37. Around 2004, I spoke to the Trade Union affiliated with the place where I used to work and they put me in touch with a solicitor who told me about

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Skipton Fund: they referred me to Sheffield Hospital which explained to me how the Fund worked.

38. I completed the application form by myself and I received the first stage ex-gratia payment of £20,000 and now I receive a monthly payment from the Skipton Fund of £1,500 (previously it was only £330).

39. I found some obstacles in getting my monthly payment because Skipton Fund did not think I was entitled to it. The nurses at RHH looked into it for me and helped me sending the application again for the higher monthly payment, which I later obtained; I am very grateful to them. The nurses at RHH have done so much for me.

40. I have been asked whether I want to make any comment or observation in relation to Skipton Fund and the financial assistance received. What I can say is that it has been really very hard to ask Skipton Fund for financial help because everything was means tested; you have to go through so many hurdles to get a grant that at a certain point I should have not asked for anything at all. They didn't help with the cost of my wife's funeral because I had a pension and they thought I could use that and that it would have been enough; but it was not and their behaviour has not been very fair at all.

### Section 8. Other Issues

41. After I found out about my HCV in 1995, I went to see a solicitor in Newcastle for some advice about what to do going forward. I found out that the Hepatitis C Trust were in the process of bringing a group litigation class action claim to the High Court on behalf of those infected with HCV. I joined with the other claimants and although it took some time, we won the claim in 1998.

42. Despite the judge awarded £13,000 to each claimant he told us that we were not going to get rich from the claim. My legal fees were very high and



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what I actually brought back home was roughly £6,000 in total. It was good that we were able to bring the claim and to win the case because we would not have received the £13,000, which was rightfully ours anyway.

43. In terms of my expectations from this inquiry, I would like to know why the Government did not step in and stop the infected blood being circulated earlier than they did. Blood should have been tested in 1991 and this was when I became infected.

44. This whole situation feels even worse to me because as everything happened in 1991 I believe I was one of the last people to receive the infected blood; I need to know who was responsible for that. I know that a few individual Members of Parliament knew what was happening, but they did not make an attempt to stop it until much, much later.

45. I need answers as to why this happened because a lot of people have died from this tragedy and I hope that I am still alive to be able to see everything finally sorted.

### Statement of Truth

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

Signed GRO-B

Dated 16.01.19.