

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN2118001

Exhibits: none

Dated: 29th July 2020

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 23rd April 2020.

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

Section 1. Introduction

1. My name is **GRO-B**. My date of birth is **GRO-B** 1963 and my address is known to the Inquiry. I am married to my wife **GRO-B** who is a **GRO-B**. We have a son called **GRO-B** who is twenty years old **GRO-B**. **GRO-B** I intend to speak about my experience of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.
2. I wish to remain anonymous for this statement.

Section 2. How Infected

3. I have haemophilia A, which is severe and I was diagnosed with haemophilia around 1967. I would typically receive SNBTS produced Factor VIII derived from NHS blood donations to treat my haemophilia. I also received an American blood product that I cannot remember the name of that was also supplied by the NHS. I remember that this product was one I could take on holiday and did not have to be refrigerated. I was under the care of Professor Lowe at the Glasgow Royal Infirmary Haemophilia Unit to treat my haemophilia. Until the mid-1980s, I would typically only receive treatment when I had a bleed, this would have been at **GRO-B** Hospital when I was a child and then at the Glasgow Royal Infirmary after the age of sixteen. After the mid-1980s I would take treatment at home, only when I had a bleed. From 2000 until the present day I receive prophylaxis which I take every three days at home.

4. I was infected from the Factor VIII I received to treat my haemophilia. I believe I was infected sometime between the early 1980s and the late 1990s, I would not be able to identify an exact date.

5. I started to hear about blood products suddenly being heat treated and saw the HIV adverts on television and wondered if that was why my treatment was being heat treated and I really started to worry. But I was a young lad **GRO-B**
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GRO- and thinking about finding a girlfriend for my future, so I was kind of in denial unless I was confronted with the problem.

6. I found out that I had the infection at the Haemophilia Unit at the Glasgow Royal Infirmary, I cannot remember the exact date of my diagnosis. I was asked to come in one day so that I could be tested for HIV. I knew there was something wrong as they were taking a lot of blood from me and sending it away for testing. It was just after they had tested me for HIV and told me I had tested negative that I was given my hepatitis C diagnosis. I was so relieved I had been told I did not have HIV and then straight after that, the staff nurse, **GRO-D** casually said "Oh but you do have a kind of hepatitis that's not A or B its

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nonspecific. Don't worry about it, it's nothing serious". It was confirmed by the Haemophilia Unit in the Glasgow Royal Infirmary that day, that the blood products I received from them, was how I became infected with hepatitis C, and from there only. There was no explanation of what hepatitis was and no information about how serious it was going to be for me in the following years. There was no internet then to find out what it was and I only started to understand the magnitude of this hepatitis infection years later when I was referred to a liver specialist, I cannot remember his name, who told me the implications of this infection and that I would have to have regular ultrasounds. The worst thing was that the specialist told me that there was no cure and the infection was really serious. I was really depressed after this initial meeting with the specialist and really had to dig deep in to my West of Scotland "be a man, get over it and just keep going" ethos, because there was only me to help me, no one else. There was no psychological help offered to me.

7. Frequently in the early years of my infection, it was often falsely assumed by doctors and hospital nurses that I had the infection because of drug taking or sexual misconduct, which I found very upsetting and I had to correct and gain acknowledgement from these medical professionals that I was a victim of infected blood products. This left me very reticent of revealing my infection to anyone unless I had no choice. This really made me feel very isolated and alone over many of the years I had to deal with this infection. I only started to let some close people know in recent times because it was plastered all over the media.
8. Thankfully, my Mum and my Dad and my older brother were not told by the Haemophilia Unit about my infection, I am sure that information would have been too much for them. They had been coping with bringing me up as a haemophiliac, which I am sure would have put immense strain on them all already, without hearing that I had now been given a fatal disease through negligence by the very treatment that had made my life viable. My then girlfriend, who is now my wife, found out when I told her. I was sure that was going to be the last time I was going to be in a relationship with her, but her

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love was so true for me she wanted to get married despite this infection and I am forever in her debt to her for that.

9. At my diagnosis, I wasn't told anything about my infection. I only really started to understand this disease once I was referred to that liver specialist years later and once the Haemophilia Society started posting articles in their magazine about the disease. Also when the internet became available to me, I found out a lot of information through that. But there was nothing at my diagnosis.
10. The information I was provided with was not adequate for me to manage or understand my infection. I was not given any information by the Unit really and I had to research myself to find out that things, like Milk Thistle, fasting and abstaining from alcohol would be something I could do to try and delay the onset of liver cirrhosis.
11. I should have had information about my infection earlier from the Haemophilia Unit. It should not have been left until I eventually saw the liver specialist, for me to be provided with essential information about the infection. I was pretty much in the dark about what would happen to my health until I had appointments for liver scans with that specialist. Even then, not much time was spent giving me information or support. It was all mainly focused on me receiving the ultrasound scan.
12. The way I was told about my infection was ghastly. It was just such an afterthought, I felt belittled. The main focus was on HIV and to be told I had tested negative for HIV was so joyous, and then to be told immediately after about the hepatitis, was horrible.
13. I was not told that others were at risk by cross infection, but with **GRO-B** **GRO-B** me being in hospital regularly over the years with haemophilia, we quickly worked out that it was going to be a risk for her and any children we might have.

Section 3. Other Infections

14. After my hepatitis C diagnosis I was tested for human mad cow disease or Creutzfeldt-Jakob disease. I was tested when they became aware that this could be passed on through blood donations though I cannot remember the exact date I was tested. To be honest, I am trying not to think about this further infection because I think that it would tip me into madness. I have struggled to cope all my life with haemophilia and hepatitis C, and I think I am just about at my wits end with it all. I do not want to think about it, but I am sure they tested me and said I had been exposed to Prions. After they told me that, I said to them I did not want to know because I was so afraid of the disease and what it does to you, I just went into denial. I have hardly spoken to my wife GRO-B about it because the implications of succumbing to this are just too difficult for the two of us to comprehend. I have not told my son or my family as it is just too horrific to let them find out about the implications for me and how I will end my days. I would rather it only came between us all if it causes my health to deteriorate. Then it would be more like a death from cancer or something, rather than being aware of the Sword of Damocles before it started to take me.

Section 4. Consent

15. I am sure I have been tested without my knowledge. In the early years of HIV and hepatitis C I had an intense period of blood tests. It was never made clear to me what these blood samples were going to be used for.
16. I was never asked for my consent for any of the blood samples that were taken from me. I was just told to roll up my sleeve and they were taken every time I was asked to attend the Unit.
17. There was no adequate information given to me about any of these tests.
18. I could not say whether I was ever treated or tested for the purposes of research.

Section 5. Impact

19. Having haemophilia, it was inevitable that I was going to deteriorate as I got older. In the seventies, I was a very active and strong person full of energy and vitality. When I got infected I found that I was suddenly prone to bouts of incredible fatigue and through the eighties and nineties I only achieved all my goals through sheer determination and pure grit, but it really took its toll on me physically and mentally. I am convinced that if I only had haemophilia, I would have achieved even more of my goals and I do not think I would be as affected as I am now.
20. As a result of my infection I now suffer from constant fatigue. I have also developed arthritis. My arthritis has slowly progressed throughout my life as my joints have become more damaged from haemophilia but it became a lot worse after I contracted hepatitis C. After my treatments for hepatitis C, my skin became very sensitive to heat and sunlight. This causes my skin to itch at random times.. I also have pains in my liver from time to time.
21. The first treatment I received for my infection was Interferon injections. I cannot remember exactly when I began this treatment but it was around 1994 or 1995 and lasted for three months. I received this treatment through the Glasgow Royal Infirmary under the care of Dr John Morris. This had to be injected in to my stomach and it was really difficult to do this at work. I had to inject it in the toilet at work so that no one would know I had hepatitis C. This treatment made me feel as if I had the flu all the time and when it was compounded with my usual arthritis from the bleeds from haemophilia, I felt like I was only just about coping with the fatigue. I was bringing up a son and working and it was incredibly debilitating to be able to function as a hands on Dad GRO-B with such a high workload. When I got through this course of injections, I was told the treatment was unsuccessful. I was in a deep depression and in despair about what was going to happen to me. But I managed to soldier on and function to a high enough level that I was never a burden on anyone.

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22. The second treatment I received was a combination of Sofosbuvir and Ribavirin. I began this treatment in mid to late 2016 and the treatment lasted for six months. I also received this treatment through the Glasgow Royal Infirmary. . This treatment successfully cleared the virus. It was thankfully a course of pills and not injections. I had to go through the humiliation of being given these pills by the pharmacist personally in front people queuing for their prescriptions. I think this was because the treatment was so expensive. So I had to endure the pharmacist assuming I was probably some sort of drug addict because I had hepatitis C and also people eaves dropping on the conversation I was having with the pharmacist. This, I had to go through for months until I had received the full course of pills for the treatment. I also had to attend multiple appointments to see my progress with the treatment to check I was taking it all correctly. This was really stressful as I had to get away from my work to attend the appointments and then catch up with deadlines for my work later. I was so afraid that I would miss one of the pills because it would lessen the chance of the treatment working. The thought of a possible second failure of the treatment put me under immense stress and worry. The treatment was successful thankfully.
23. The only difficulty I had in accessing treatment was the length of time I had to wait to receive it. I had to wait a number of years after my diagnosis before I began my first treatment in the mid-1990s.
24. Although I am grateful that I received the initial Interferon treatment, I feel I should have been offered PEGylated Interferon as I heard that this had a greater chance of working with my genotype. I am unsure why I was not offered this instead of just plain Interferon.
25. Due to my infected status, my dental work is done at a hospital dentist, at the GRO-B I think this is because no normal dentist would have accepted me because of the hepatitis C. Every time I gave a blood sample for my doctor I had to go through the process of explaining and warning the nurse that I had hepatitis C and to be extra careful. This made me feel like a modern day leper and really took its toll on my mental health. Some

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medications I have taken have required extra monitoring and tests because of the hepatitis C and I found all this extra testing and monitoring really impacted my time at work and my mental and physical health. I had to travel to and fro to meet all these appointments whilst being fatigued and prone to bleeds because of my haemophilia.

26. My infection has had a big impact on my private life, in so many different ways. My infection made me feel like I was always a possible danger to people in my life, the risk of cross infection was always something that was on my mind. That thought made me feel like a leper. I would always have to sterilise everything if I ever got a cut for example, for safety. I remember I would always make sure I watched a cut until it had properly healed in case I infected anybody from it. I would also be dealing with the worry that my condition could deteriorate at any moment and that I would become a burden on my family if I became seriously ill or died. The infection also meant that I was struggling with constant fatigue and I would have to continually dig deep within myself to get through all I had to do each day. Personally, I was also dealing with the stress of keeping the infection a secret, the stigma of the infection was something I always worried about.
27. The infection impacted my family life as well. I remember when my son was a baby and toddler, I would be totally paranoid to hold him in case I infected him. That fear would cause untold stress and anxiety. Preparing food as a family was also something that became a point of stress because of the fear of cross infection. The fatigue I would suffer from, would cause me to feel a lot of guilt at times because I would often not have the energy to participate in family activities.
28. Seeing the hepatitis C scandal in the media meant that my friends and family would often ask if I had been infected. I always had to lie to them and say that I was one of the lucky ones that hadn't been infected. It was quite difficult to maintain that face in social situations. My infection also meant that it was not advisable for me to drink alcohol. Avoiding alcohol in West of Scotland social

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occasions is impossible. So I had to drink to fit in and felt I was taking risks with my liver.

29. There was no stigma for my family as I kept my infection a secret. This has been very stressful over the years. The stigma was all on me and I only encountered it in an NHS setting when people were dealing with my body fluids. I managed over the years to conceal it. I am sure I did not get a lot of job interviews because I had to declare that I was infected in the application forms.
30. My infection has had a great impact on my career. I avoided going for promotions or other jobs and stayed in the same job because I knew that I could only just about cope with the workload in my current position with the fatigue I was experiencing and all the medical appointments. I didn't know if other employers would have been so understanding about appointments or the levels of workload, so it definitely stopped me from moving on in my career.
31. I am sure if I had not had hepatitis C, I could have pursued much better **GRO-B** **GRO-B** and earned a much higher salary and had a higher level of **GRO-B** **GRO-B**. I believe this because I have an excellent degree from **GRO-B** **GRO-B** and also I have an above average ability in **GRO-B**. I curtailed my career ambition because of hepatitis C and instead, focused on having a job that suited my physical and mental state brought about by my infection. I believe I have suffered financially because I was limited by my hepatitis C infection.
32. My wife has suffered because of my infection too. She has had to watch me experience fatigue, pain, anxiety and the curtailment of my career. She has also had to live with the fear of my death and the possibility of me leaving them to cope on their own if I die. She has had to watch me suffer from the treatments I was given for hepatitis C. She has also had all the worry that I might infect her or our son by accident. Although I have worked throughout my infection, played a full part in the functioning of our household and have been a hands on Dad throughout this ordeal, she knows that I have done this by fighting

through all the physical and mental drag of hepatitis C and she has suffered knowing this.

Section 6. Treatment, Care and Support

33. I have faced difficulties obtaining treatment. At one stage I heard that there was a new Factor VIII treatment that was created by using recombinant methods. I realised that this would have no human blood involved and that meant no more risk of picking up a virus from blood. I was told by my consultant Professor Lowe that the treatment was not available to me because of the cost and my health board was only funding the treatment for children at that time. . I was desperate to get away from Factor VIII derived from human blood because of the risk of even more infections. Professor Lowe encouraged me to make direct contact with the Argyll and Clyde Health board to plead my case for funding as I did not want to take any more human blood derived treatment. I contacted the Health Board and told them that I was stopping taking the human derived blood products for my haemophilia and that I was prepared to take the risk of bleeding to death or take on more joint bleeds to protest against their decision not to purchase the artificial treatment. This was a very stressful time as I had to personally fight for the funding. My joints greatly deteriorated around this period as I took less treatment than was realistically required to treat joint bleeds as with each infusion I had a fear of contracting further infections. The Health Board yielded and agreed to supply the treatment to all haemophiliacs. This caused me even more stress on top of how I was and I was close to having a breakdown because of this situation.
34. I have never been offered any counselling or psychological support and the only support I have ever received was from my wife because she was the only person who knew I had hepatitis C. The nursing staff in the Unit tried their best to help me but that is not their remit.

Section 7 Financial Assistance

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35. I received a lump sum payment from the Skipton Fund of £20,000 around 2004 or 2005. I found out about the Skipton Fund through the Haemophilia Society magazine HQ. For the Skipton Fund payment I had an application form posted to me which I filled out and sent away. I remember when I applied for the one off Skipton payment, I had to fill in a form to say that I would not seek any more legal action against the Government. I did not face any difficulties in applying to the fund.
36. I also receive a monthly payment of £525 from the SIBSS. I started receiving those payments in 2017. I also heard about this fund through the Haemophilia Society magazine HQ. To apply to SIBSS I went to the website and downloaded an application form. I did not face any difficulties in applying to the fund.
37. I was grateful to the Scottish Government for making the allowance available to people affected by hepatitis, however, when I got the claim form, there were three levels of allowance. I felt the way it was worded made it seem that the higher level payment was impossible to achieve even though I have suffered greatly. I felt obliged to claim for the middle level of allowance. I do not think it should have been means tested like that and it should have been a standard allowance for all.

Section 8. Other Issues

38. I have nothing else to bring to the Inquiry's attention.

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Statement of Truth

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

Signed **GRO-B** _____

Dated Aug 27, 2020