

ANONYMOUS

Statement No.: WITN0006001

Exhibits: NIL

Dated: 28/02/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28th February 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B My date of birth is GRO-B 1963. My address is known to the Inquiry. I wish to remain anonymous because I am a Haemophiliac and I am still infected with Hepatitis C. I do not want everyone to know this. I currently live alone. I have 8 children in total. Four boys and four girls by four different mothers with whom I had long relationships. I currently have six grandchildren. In this statement I intend to speak about my experience contracting the Hepatitis C Virus from infected blood products, the treatment I have received, and the impact it has had on my life.

ANONYMOUS

Section 2. How Infected

2. I was born in a different country and my grandmother looked after me whilst my parents built a life in England, with my siblings. My grandmother noticed that after I had started to walk, I was getting lumps and bruises on my joints but nobody really knew why. I cut myself once and it just wouldn't stop bleeding. The medical facilities were very unsophisticated where I was from. My grandmother was a herbalist and dealt with my bleeds in a homeopathic way, by making herbal mixtures.
3. My younger brother, who was in England, would wake up in the night with continuous nose bleeding. Mum took him to the hospital and was told that he had haemophilia. My two brothers and I were all later diagnosed with the same. The female members of the family were carriers and so I have many male cousins and nephews who are Haemophiliacs.
4. My grandmother was getting old and I required access to better medical care and so I came to join my parents in England on 22nd February 1974 when I was ten and a half. I had tests which showed that I only had 1% clotting in my system, when a typically normal level should be around 50%. I was diagnosed with Haemophilia A, the most severe. Anything above 4% is haemophilia B.
5. When I first came to the UK, I had a bleed and was given cryoprecipitate. It looked like orange juice and it was intravenous. Whenever I had an issue and went to the hospital, this is what I was given. A lot of the cryoprecipitate wasn't pure because I could see that there were streaks of blood in it. The cryoprecipitate was concentrated from plasma, and then later, when the Factor 8 was developed it was even more concentrated.

ANONYMOUS

6. When my knee was blown up with swelling the medics tried to relieve the problem by poking a syringe needle inside to release fluid, they called it 'aspiration'. They thought that was the problem. However, this wasn't the case. The tissue was swollen because of the scarring over the years.
7. When I was 11 years old Dr Bletcher and Dr French treated me at the Queens Medical Centre (QMC) in Nottingham. One day Dr Bletcher said to me "don't worry by the time you have children this will be sorted out, we will find a cure for it". This still hasn't happened.
8. In 1975 I was told that I was given 'factor' blood product made from pigs blood. It wasn't orange and it wasn't cryoprecipitate. It was clear. A few of minutes after administering this, my chest tightened up and I couldn't breath. Normally, I would have a reaction, but not like that. The doctor that administered it came back to give me a syringe of Piriton antihistamine. I remember that my dad went mad.
9. I was being treated with Factor VIII from 1980. They started teaching me how to self-administer at 12 years old. Prior to that I would have to be taken out of school when I had an episode and go to hospital to be given the 'Factor'. An ambulance turning up at school to take me was a weekly event and conspired with everything else to single me out from the crowd. So, self-administering made life easier in that respect. The supply would consist of purified water in the syringe, and a small vile of the right amount of Factor 8Y, which I would mix together in the syringe. The mixed liquid would go clear and I would then inject it. If I left it too long it would become thick, jelly like and I would not be able to use it. I was then able to do it at home and at school by myself. I was one the first ones in Nottingham, I think this was because my mother was a nurse. I used to take it to school and store it in the fridge at a disabled school next door. When I would feel pain and swelling, I would administer. The doctors would say its just arthritis but I knew when it was a bleed. It is most likely that I self administered the infected blood

ANONYMOUS

product. I used Factor 8Y until 2010 and then it was changed to Refacto a synthetic alternative.

10. Dr French was the main haematology doctor at QMC. When the HIV became a huge thing, he disappeared and I was told he went to get a job in Saudi Arabia. Dr Gerry Dolan replaced him – he decided to do a complete check of all haemophilia patients. This would have been in the mid to late 80s. He then told me that I had Hepatitis C and I also had osteoporosis.
11. I started receiving blood products in 1974, when I arrived in the UK, after I was diagnosed. I believe that me and my two younger brothers, both Haemophiliacs, were infected with Hepatitis C through factor VIII in the 1980's. I have Chronic HCV - genotype 1A.
12. I didn't really have blood tests until Dr Dolan. Afterwards and to this day, we do it every 6 months. With Dr French – I didn't see him if I didn't have an issue.
13. When I was told I had Hepatitis C, I said to myself that at least it wasn't the HIV. I was informed face to face that I had HCV but I was just numb to it because I was so used to being disappointed. Dr Dolan said it could affect my liver and everything that goes with it. Treatment wasn't actually discussed at the time that I was told. I was given no leaflets.
14. In terms of treatment: Some haemophiliacs went on Interferon. A Haemophiliac mate of mine had the treatment. He told me that it doesn't cure the hepatitis but makes it dormant and so therefore it can return. The majority of my haemophiliac family and friends used it. The side effects were terrible. When it didn't work their relationships went to pot, this put me off totally. I did not want to do this.

ANONYMOUS

15. Dr Dolan offered me the treatment in the 90's. He told me the chances of it working were 30%. Both of my brothers had tried treatment, it didn't work for them and so I didn't bother. My brother's side effects to the interferon were low moods, depression and vomiting. I declined the treatment.
16. I have scarring but no cirrhosis. I have always put the health of my liver i.e. that it hasn't got worse, down to the protein powder I drink. However, I decided to have treatment in 2016. I was told that there was an over 90% chance of success. The treatment was called Harvoni and the side effects were virtually nil.
17. I had the eight-week treatment of Harvoni, however I was tested positive for HCV after 4 weeks of the treatment and at this point we knew it wasn't going to cure the HCV. Initially the treatment had worked and then it relapsed. I just try not to worry about it.
18. I've had no other treatment since then. They have offered me another with different drugs, however I'm sceptical and my head just isn't in the right place to take this on. I've been given an open appointment to go and see the doctor when I am ready.
19. In June 1993, I went into hospital because I had warts on my behind. I went for a rectal biopsy and was put under anaesthetic. They asked if they could also take a piece of my liver to see how it was doing. They did this with a syringe.
20. In December 1994, one of the medical professionals had the smart idea of bringing all three of us brothers in at once. One had an elbow replacement, another had an arthroscopy, and I had my elbow done. They then stated that they wanted to take a piece of our liver from behind, near the spine. One of my brothers went down first and came back screaming in agony. I stated that I had already had one done the year before when I had the rectal biopsy, but on the medical notes it

ANONYMOUS

was recorded as having been an ultrasound scan. There was no reference to the biopsy I believe that this was a cover up because the doctor didn't want to leave any evidence of sticking a needle into a haemophiliac's liver.

21. Nonetheless, I said I would go next because I was the oldest. When I got in the room, the chap that operated on my brother didn't look right. It didn't fill me with confidence, and I requested to be taken back to the ward immediately, so only one of my brothers ended up having the procedure done. A few weeks later, this same guy was found dead. I rang the nurse that treated us and she confirmed that he had hung himself. What frame of mind must he have been in when he was going to perform the biopsy on my brothers and me?

Section 3. Other Infections

22. Apart from Haemophilia and HCV, I have Osteoporosis and Arthritis.

Section 4. Consent

23. I gave consent to receive factor VIII but I did not consent to being given it from infected sources.

Section 5. Impact

24. We grew up on a council estate and it often came up on the news that haemophiliacs had HIV and Hepatitis in the mid 80's, we had shit thrown at our door. Where I live now there was a local petition for me to be moved. There was panic and ignorance, it was a terrible time. Even before that, I remember that my friends got yellow jaundice from the cryoprecipitate in the 70s.

ANONYMOUS

25. Having Hepatitis C meant that getting up out of bed wasn't easy. I would wake up and feel drained and tired. I didn't actually put it down to that until later. I thought I was just tired, or I blamed the weather.
26. The first job I ever got was as an apprentice lace maker. After that I went off to be an apprentice printer, and then I worked for Crossland Filters. When I went for jobs, I didn't tell any of my employers that I was a haemophiliac or that I had HCV. I told them after I got the job, when I was more established. The jobs didn't last long because I needed too much time off and I was let go. This was down to all of the conditions that I had but I now know that it was because of the HCV, that I was always tired.
27. I would also have low moods and mood swings but back in those days as a man, you were not meant to be depressed.
28. If I was ever admitted to hospital for anything, I would be put in a separate room because of the HCV. This has led to me isolating myself even further. Having these special measures makes me feel very alone – it got to a stage where if I was put on a normal ward I would shut the curtain around me. It does make you feel marginalised. The greatest impact of the HCV has been the stigma surrounding it. That said, I have lived with being a Haemophiliac and so stigma from those early years of AIDS and HIV in some ways trained me for it. I felt and feel resigned to this life.
29. I had health insurance and I ended up in hospital for 3 weeks. I put a claim in and I was told that I should have told them that I had HCV and haemophilia and so my claim was rejected and my insurance cancelled. Also, when getting a mortgage they would see me as a bad risk, and this was the same with travel insurance, so I would never fully disclose my health issues.

ANONYMOUS

Section 6. Treatment/Care/Support

30. Dentists and surgeons wouldn't touch me because they were scared of touching haemophiliacs with HCV – they were ignorant of it. All they knew was this person was a 'bleeder' and has a dreadful disease. A lot of people were frightened of interacting with me. I was referred by the hospital to a specialist dentist, used to dealing with unusual cases. The first thing that is always said by the dentist is about my factor level. I tend to dose up with Factor 8 before I go.

Section 7. Financial Assistance

31. I received £20,000 from the Skipton fund and I receive the Skipton pension, which is £18,000 per year. I also get the cold weather payment in December, which is a £500 one off payment. I applied for the £50,000 one off payment from the Skipton fund, however I didn't get it because I didn't meet the criteria.

32. In addition, I am in receipt of Disability Living Allowance, Mobility Allowance, and Employment Support Allowance. I stopped working in the late 80s due my various medical conditions.

Section 8. Other Issues

33. I was born with Haemophilia, my family have lived with this throughout and so I have been used to having to deal with the effects, the impact on my life and the way people have reacted in the aftermath of then AIDS epidemic. This is what life has dealt me, it is bad luck but nobody could do anything about that. The HCV is a different matter entirely. This could have been prevented by screening and not buying blood taken from people with questionable lifestyles for money. I support this Inquiry and I hope that at long last something can be done for the many people who have been infected and their families.

Statement of Truth

ANONYMOUS

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

Signed GRO-B

Dated 28/2/2019