

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN2201001

Exhibits: None

Dated: 11th January 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 9 November 2018.

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

Section 1. Introduction

1. My name is name is GRO-B. My date of birth is the GRO-B 1954. My address is known to the Inquiry. I currently work for GRO-B GRO-B I intend to speak about my infection of Hepatitis C due to a transfusion I received. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life and the life of my family.

Section 2. How Infected

2. I believe I received contaminated blood at the tail end of 1987 or the beginning of 1988. I was taken to Ninewells hospital in Dundee at this time. I had collapsed in the house and they determined in the hospital that I had a burst ulcer. I believe I had a couple of pints of blood. I do not remember the names of any of the doctors who treated me at Ninewells hospital. I believe I was in hospital for around three or four days.
3. I did receive one other transfusion many years later in Kirkcaldy. I do not know the name of the hospital there. I believe it would have been around the mid-90s when I was in Kirkcaldy and received that transfusion. I do not recall the names of any of the doctors who treated me there.
4. I was infected with hepatitis C but I did not know this until 2001. In hindsight, I had no real symptoms that I would attribute to this other than some tiredness and fatigue. I put this tiredness and fatigue just down to work and family life. I did not suspect that it was any underlying illness caused this.
5. I found out about my hepatitis C when I came home from work one day and my wife GRO-B said that the blood transfusion service had called and said that I had hepatitis C. At no stage was I informed that there was any risk with having a blood transfusion.
6. I was annoyed after my wife received that call as they told someone else first, before telling me. I believe that I was told to go to the blood transfusion service at Nelson Mandela Place in Glasgow. There, they told me that the most likely source of my infection was a blood transfusion after going through some questions with them. I don't do drugs or anything like that so I knew that that wasn't the cause.

ANONYMOUS

7. I believe I gave blood when the blood transfusion bus came to my place of work in the year 2000. I gave blood and also said that I had given blood maybe 20 years before.
8. I was quite bewildered when I was told at Nelson Mandela Place. I cannot remember if I had blood taken around that point.
9. I do not remember much about the information that was given to me about hepatitis C but I do recall that it was quite vague. I'm not sure if they said anything about cross contamination or infecting other people. I believe they may have said that I would end up going to the Glasgow Royal infirmary at some stage. Because I was annoyed at my wife been told I think I was still quite angry when they told me the information so I do not remember much of the conversation.
10. I believe I may have went to my GP, Dr GRO-B
GRO-B prior to going to the Glasgow Royal infirmary. It may have been my GP that sent me on to Glasgow Royal infirmary. I believe when I went to Glasgow Royal infirmary I was seen by a consultant called Dr Morris. I do have a letter from that consultant, I believe, saying that it was most probably a transfusion that I was infected by. For most of my visits I saw a Dr Forrest and a number of specialised nurses. I went there every 3 to 6 months. The doctors there were very nice.

Section 3. Other Infections

11. I was infected only with hepatitis C.

Section 4. Consent

12. I never had any blood taken between my transfusion and diagnosis so I do not believe that there could have been any tests done on my blood without my consent or for any other purpose.

13. I do recall when I was undergoing treatment that I was asked if my blood could be kept for research. I did say that was all right.

Section 5. Impact

14. I have now developed an underactive thyroid due to the interferon treatment I had. I feel the cold and often get dry skin. I was never told of any side-effects that I may have prior to receiving the interferon treatment. When I told one of the nurses, who I do not remember the name of, about these side-effects she said that it was common for these side-effects.

15. I believe it may have been in around 2010 or 2011 that I had interferon and a ribavirin treatment. I had liver function and blood tests taken frequently during the course of this treatment. I was already taking milk thistle for my liver health anyway. I had my first treatment of this in hospital and then self-administered for a period of three months. I was non-responsive to the treatment.

16. I was made emotional by this treatment; it did seem to affect my emotions. My wife GRO-B thought that I was a little more tetchy and less patient. I was a wreck at times with not eating and sleeping very well. I would say mentally and physically, I was not a good place at that time. I had more flu-like symptoms such as fatigue which generally got worse on treatment. I also suffered from brain fog where I could not focus or concentrate on any one thing. Sometimes I would realise I was speaking absolute gibberish.

17. I had a second round of treatment in 2017. This was a combination of ribavirin and PEGylated interferon. This was in tablet form. I took this treatment for around 3 to 4 months, I believe. I was up at the hospital at Glasgow Royal every couple of weeks. I recall that there was a nurse there called Sheila who had looked my results and said the treatment was going well. At the end of this treatment I was told that the virus had cleared but I was also quite concerned about what damage had been done my liver already. I have previously had a liver biopsy but not in the last 5 to 6

ANONYMOUS

years. I believe now they do fibre scopes but I have not had one in the last three years. I believe my most recent meeting had a reading of 6 or 7 and they said that that was okay. Throughout the second round of treatment I did have the same symptoms as the first treatment.

18. I now suffer from an underactive thyroid. I am on thyroxine for this and thankfully this medication does not have any side-effects that I am aware of.

19. I suffer from chronic joint pain and have had two knee cap replacement operations in the last few years. It is difficult to complete tasks without feeling sore.

20. It took quite a long time for me to actually get treatments. I was happy to go up and give blood and did not ask about treatment. I felt the stigma when I was a hospital, it felt like people looked at me differently. I felt that people looked at me like I was druggie. I would sometimes go to an open clinic and it felt like people were looking at me like a druggie and I felt very embarrassed about this. Eventually we were moved to another unit away from that main clinic. Some of the doctors and nurses were very good but some others felt like they were treating you differently because they assume that you had maybe got hepatitis C from a choice made through life, rather than through the means that I ended up with hepatitis C. I felt like I was treated like a leper at times. I believe that my treatment generally improved if I was seeing someone more than once, as opposed to when it was a new member of staff. I found this all quite traumatic at times.

21. I do not believe that my hepatitis C diagnosis had any impact on any dental treatment I required. I had always paid for by dental treatment anyway but that was also through the NHS. My dentist was fine with hepatitis C diagnosis when I disclosed this to them.

22. I never felt held back in terms of the treatments being given to me. Dr Forrest gave me some hope for new drugs coming out over time that

ANONYMOUS

would work to help with my hepatitis C. I did feel that sometimes the cost factor was at play, down to the cost of what treatments they could provide. I believe there was somewhat of a pecking in order in terms of how damaged someone's liver was and those who had a more damaged liver were given treatment sooner.

23. In terms of my family life, I'd say things are fine now but when I was first diagnosed I had a very hard time worrying about infecting my wife and children. I felt very guilty. My wife and I have

GRO-B

GRO-B

GRO-B

GRO-B

24. My wife was tested, I believe, five or six years ago. test came back negative. I am unsure if the children got tested, I believe when they were 18 they may have got tested.

25. The children have known as they've gotten older but we never actually hid my hepatitis C from them.

26. The fatigue that I suffered meant that I could not do things the children that I would have liked to have done. As I have said at the time I believe this was just down to the tiredness from working life. I think they did suffer and it did affect our relationship to some small extent. It also affected my relationship with as well that I was not able to spend more time with the children.

27. When was younger, we would go out and play football or go on bikes but the fatigue that I suffered did limit this.

28. In terms of how my social life was affected, I would say that I'm not the sort of person who is very outspoken but I did withdraw after my diagnosis. I lost a little bit of a spark I had before. I was worried about it coming up in conversation. I used to go to the football but I feel the cold unless it's a

ANONYMOUS

particularly hot day and I do struggled to go to this. Sometimes I feel that going out is too much in one go with the anxiety I feel now. My wife has said that I am more socially anxious. I would say that I am generally more anxious than I would have been before. My work is changing premises and changing to shift work and that does make me quite anxious.

29. With my work I used to do a stand-in role for my boss sometimes. I did eventually stop doing this at times due to my fatigue. There was plenty of overtime on offer but I could not always do it because I was too tired. I do believe that I probably did lose out on opportunities to advance my career. I have been there for 20 years and I feel that I could have advanced more had it not been for the fatigue I suffered. I believe if I felt more normal, I would have been more driven to advance and try and be promoted. At time I just wanted to survive and be able to put food on the table for my wife and children. I believe it did stifle my ambition in the last 15 to 20 years. I lost my enthusiasm for my job should which I did enjoy. It became more of a chore. In the last 5-10 years I'd say it's more of a means to an end as opposed to a career I did enjoy.

30. I believe that my diagnosis has also had an impact in terms of getting a mortgage and life insurance. I'm now no longer covered by life insurance due to my hepatitis C. I believe that our initial mortgage for our first house was not affected but when we moved to [GRO-B] in 1996, it was then affected. I think this may have meant that the house may only be in [GRO-B] name.

31. I do not believe that my diagnosis had any impact on my children's school performance.

32. My wife [GRO-B] has been my rock throughout all of this. I would say that she has seen everything that has gone on and is probably more bitter than I am and a bit more vocal. [GRO-B] has had more of a wider view on how all this has affected the family. I think she is mostly just annoyed at the injustice of it all.

Section 6. Treatment/Care/Support

33. In terms of support offered, I believe that I was given brochures when treatment was being discussed. I was given a helpline number but I think it could possibly have benefited from actual counselling. If they had said that you may go through a litany of emotions, I would have at least have been in some sense prepared for what was going to go through. I believe I could have benefited just from being told that or from counselling being offered. Because of the stigma of hepatitis C I did just want to keep it myself. I would certainly say that what support that was offered, which was none, was inadequate support.

Section 7. Financial Assistance

34. I did receive money from the Skipton trust. I do not know if I just read about it somewhere but I think I must have. I do not think that any medical professionals had said to me about this. I recall that there was something to do with Lord Archer and Lord Ross, it may have been through that that I learnt about Skipton. I received a lump sum of £20,000 in 2004 or 2005. I have not received any other payments. I found this to be easy process. I was sent a form and was given a reference number to quote. I believe Professor Morris had done a letter for me for this.

35. I do believe I got a £500 payment for heating allowance at one stage. I think this may have been Skipton as that rings a bell more than Caxton.

36. I am now receiving money through SIBSS. This started in December and I believe it was when I went in SIBF meeting in September or October that they told me about this. I believe there was some mention of the people from the enquiry being there and a Professor Goldman suggested that they would count stage ones and that's where self-assessment was proposed. I do not think the forms overly intrusive nor did I find it difficult to self-assess. There was a man at the Scottish infected blood forum who

ANONYMOUS

helped. I did mark myself as severe as that is how I feel I've been infected.
I believe I am now receiving around £1500 per month.

37. I would say that the financial assistance that has been offered was
inadequate before but is now getting better.

Section 8. Other Issues

N/A

Statement of Truth

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

Signed

GRO-B

Dated

12/2/19