

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN2131001

Exhibits: WITN2131002-010

Dated: 29th 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 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** 1954. My address is known to the Inquiry. I am retired now after having previously worked in the **GRO-B** in a secretarial/admin role. I was infected with hepatitis C following a blood transfusion in the late 1980s. I am still infected and suffer from chronic hepatitis C.

Section 2: How Infected

2. I believe I was infected with hepatitis C during a transfusion in an operation I had in 1986. It would have been the 30th or 31st so we just been coming up on 33 years since my operation at the time I'm giving

ANONYMOUS

this statement. The operation was a myomectomy – a surgical procedure to remove uterine fibroids. I believe I was given several units of blood but I do not know how many. This was at Crosshouse hospital and my consultant was a Mr MacDonald. I had a hysterectomy in 1993 but I did not receive any blood transfusion during this operation and it is most likely that my infection occurred as a result of the 1986 operation.

3. I was told I had hepatitis C in December 1995. My sister GRO-B who looks very similar to me - had gone to see her GP. While she was there, he mistook her for me and started to tell her something that had been meant for me. Before he divulged anything, my doctor realised that it was in fact my sister and not me.. My sister then told me he had said to make an appointment with the doctor, which I did. My doctor, who has since retired, was GRO-B
GRO-B

4. When I went to the doctor he said that he had received information after a "lookback exercise" which said that I may be infected with hepatitis C. I believe I had my blood test in the GP surgery. I was called back weeks later to be told that it was a positive result and I did have hepatitis C. This would have been in December 1996. I exhibit confirmation from the Scottish National Blood Transfusion Service that I had contracted hepatitis C as **WITN2131002**.

5. My doctor said that it was nothing and he did not think that anyone would want to see me about it. I feel that he was ill-informed. He said he didn't think there would be any follow up that was necessary. I was left gobsmacked and adrift at the end of this. I have now had shown to me my medical records from the time and I can see that Dr GRO-B had been told that a specialist referral "was advised in all cases" and for that reason had written to Dr Mills at Gartnavel hospital in Glasgow to request his opinion as to whether a specialist referral would be needed in my case. This letter is dated 15 January 1996. I was not aware of this at the time and he gave me no indication that he would be seeking a specialist

ANONYMOUS

referral. While it is my understanding that notes from my medical records state that a specialist was instructed, this was not fully conveyed to me. I was told, by my GP, that no one else would want to see me. The GP made my condition seem unimportant. I exhibit a request from my GP, Dr **GRO-B** to Dr Mills, for a consultation as **WITN2131003**.

6. I assume that Dr **GRO-B** was advised to refer me to a specialist, as shortly after my appointment with him I got a letter from Gartnavel hospital asking me to attend there. I went there and saw Dr James McPeake, I recall he felt my liver but I do not really remember anything else that he said. I have now seen a letter sent by Dr McPeake to Dr **GRO-B** dated 14 March 1996 which confirms that I acquired hepatitis C from the 1986 blood transfusion. This letter is exhibited to my statement as **WITN2131004**.
7. I believe the Dr McPeake gave me advice about any cross infection and mentioned things like sexual activity and sharing toothbrushes and needles. He gave me the "worst case" scenario that in 25 years time I might deteriorate and may even die as a result of the infection. I recall that my sister was with me when I was told this. I recall that the information I received seemed quite generic and basic. It was only when I joined the Scottish infected blood forum in 2012 and began to attend meetings in 2013 that I got a lot more information. I wasn't really able to go until I retired and since I retired I have had time to go. I believe that I found out about SIBF through Thompsons Solicitors.
8. Shortly after I was diagnosed I wrote to Crosshouse hospital as I was attending Gartnavel and I wanted to find out what happened in 1986. I do not recall when I asked this. I received an answer from someone called Laurence Marcantonio. He invited me for a meeting at Crosshouse. I attended the meeting with my sister. When we attended the meeting, Mr Marcantonio had a woman with him whom I believe was the head of the Scotland's blood transfusion service at the time. I thought I was meeting only him. The other person that was there was a Dr Myrtle Peterkin. I did

ANONYMOUS

not feel that Marcantonio had a positive attitude towards me and I could tell that he was not happy we were there. Dr Marcantonio asked why I was there and I said I was there for answers. It felt like they were a good cop bad cop situation. He was furious and she seemed really nice. I recall him saying "Do know how hard it was for my staff to find all you people". I felt that Peterkin was trying to placate me but they both essentially said that it was a tragedy but there was nothing that they could do. They did not offer any answers and were really quite defensive. I recall that, without me even mentioning compensation, they told me that there would be none.

9. I do feel that the information I was eventually given about my infection and the circumstances which resulted in my being infected should have been given to me earlier. The other issue was the information I was given at Gartnavel was entirely different from what I was given by my doctor. I felt my own doctor never really took it seriously, possibly due to his lack of knowledge about hepatitis C.

Section 3. Other Infections

10. I was infected only with hepatitis C.

Section 4. Consent

11. I do not believe there are any issues in terms of when I was diagnosed in relation to consent. I had no blood taken where I think could have been tested. I am aware that I allowed samples of my blood to be used for the purposes of research and there is a consent form within my medical records for this, which I exhibit as **WITN2131005**.

Section 5. Impact

12. Prior to my diagnosis, I did often have flulike symptoms such as aches and tiredness and fatigue. I also suffer from "brain fog" and I felt that if I

ANONYMOUS

got ill it lasted longer than it would for normal people. This is still true now that I feel that when I have a cold or flu it lasts longer. The flulike symptoms really just became part of my life. Over time they just got more constant. It was a total shock when this happened. I did mention on each of my multiple visits to the doctor that I was suffering from these symptoms, although I am aware that these may not necessarily have been recorded within my medical records. It was in the 1990s that my symptoms started to manifest. I am not the sort of person to dwell on things, and was much more the type to get on with things.

13. I do not believe I have had any medical complications that have arisen purely to hepatitis C. A liver biopsy said that there was some scarring and then a couple years later I had another that said there was nothing.
14. The year when I first had the treatment, in 1997, was difficult as I had to juggle work as well as treatments and it was a long, drawn out, exhaustive procedure. I was told by a nurse that hair loss might be a side effect of the interferon. I did feel these symptoms for a couple of years. Even now I still find that my hair loss has affected my hair, although as my hair is curly, this is well-hidden. I did also suffer from exhaustion during this treatment. The symptoms started almost immediately after the first interferon injection.
15. After diagnosis, I really felt that I was just not myself. The way I spoke to people was very different. I would almost describe what I feel as being socially claustrophobic. If someone came into the office, I would feel claustrophobic and not want them to be there. I do believe my family suffered more and I took it out on them, even shouting at my mum who was in her 80s. My emotions were all over the place the time. This started during the 1990s I believe, although I cannot recall the exact timeframe. I believe that the Ribavirin in my second treatment was what caused the emotional response. My psychiatrist, Dr Simon Tang, gave me an antidepressant called Citalopram, which I still need to take despite trying to come off it.

ANONYMOUS

16. Interferon has caused damage to my thyroid and I am now on thyroxine for the rest of my life. I found out about this through a phone call from a nurse at Gartnavel who said that I needed thyroxine. I started my thyroxins treatment in 1997, when the first treatment damaged my thyroid gland. I exhibit a letter from Nurse Liz Spence discussing my thyroxine treat as **WITN2131006**.
17. I am still affected now with hair loss and difficulties with hair growth. I do believe this is, in part, due to the treatments. I currently have partial alopecia. I never had any mental health issues before this.
18. In terms of the effects on my work, I probably would have tried for promotions had it not have been for my symptoms. I believe that my condition stifled my career progression as I was worried about being off sick and that affecting my chances of being promoted and continuing up.
19. I have felt some financial effects as a result of my diagnosis. The amount of times I've had to go up to Gartnavel has cost a lot, even just in terms of paying for trains. I was able to arrange my working hours around my treatments and trips to hospital by working flexi and over-time. I do not have life insurance as I am put off by the thought of having to go into my medical history and the likelihood that I would be turned down or have to pay a very expensive premium.
20. In terms my social life, I do not drink any more. For a long time I was at home and in bed at 10 o'clock at night as I was too tired to do anything. At the age when I was diagnosed, I feel I would have been far more sociable had I not been living with hepatitis C.
21. Diganosis also had a real impact on my family life. I have always been very close to my mother and sisters but I felt I would lock myself away at the weekends and spend less time with them. As I have already

ANONYMOUS

mentioned, I was more emotional and would take it out on those closest to me.

22. I do believe the stigma played a big part in how the diagnosis affected me personally. I'm a very private person, even when I go to the GP surgery if the receptionist is someone I know, I don't like the idea them knowing about my condition. One time I recall that there was a younger girl working at reception and I knew her parents, I was very aware of the fact that she had access my medical records.

23. I even recall the HR people at work asking me how I got it. I do think I possibly did lump it in with the HIV and AIDS crisis of the 1980s and early 90s. I do think of it as dirty blood. I was very wary of it coming up in conversation and only really my family and medical people would know.

Section 6. Treatment/Care/Support

24. I had my first treatment in 1996. This was interferon and this was for 48 weeks. I lasted the full course but this was ultimately unsuccessful. I had only started my job at the GRO-B a year before. I was very worried about my job security at that time. I recall at one stage I had to take Wednesday afternoons off to go to be checked also to collect my interferon treatment. I was injected three times per week. A letter from Dr Mills to my own GP, Dr GRO-B is exhibited as **WITN2131007**.

25. My first symptoms following my treatment were severe – it felt as if I had been hit by a train. I was very tired and even more flulike than I had been. It really knocked you for six. I found that I have very itchy skin and my hair was coming out. It felt a little bit like ants all under your skin and you are aware of it all the time.

26. I do recall that during my first treatment, they told me one point that my hepatitis had disappeared and then told me it had reappeared. I exhibit a

ANONYMOUS

letter from Elizabeth McCrudden, consultant virologist, to my GP, Dr **GRO-B** as **WITN2131008**.

27. I received my second round of treatment in 2009. This was a six-month long course of Pegylated Interferon and Ribavirin. This was once a week for injections and one tablet a week as well.
28. With the second round of treatment I suffered the same symptoms as before. I thought I was fine and then with one visit to hospital I felt that I cried a lot. I had a low mood and had trouble sleeping. They said it was probably the ribavirin that caused the emotional response. I was referred to the Infection Tropical Medicine and Counselling Service at the Brownlee Centre at Gartnavel where I was under the care of a psychiatrist, Dr Roger Wong. I have had shown to me and now exhibit as **WITN2131009** a letter to my GP from Dr Wong dated 26 November 2009 which shows that I was diagnosed as suffering from Interferon induced mood disorder. It was at this stage I was first prescribed Citalapram (an anti-depressant) 20mg daily.
29. One of the nurses at Dr Mills clinic told me that because I have genotype 2, this should have been one of the easier types to treat and the treatment should have worked but it did not. This would have been around 2009/2010. I exhibit a letter from Dr Mills to my GP, Dr **GRO-B** identifying me as a non-responder to combination antiviral therapy as **WITN2131010**. I was obviously disappointed when I heard this. I've been put on a list of non-responders and have been told that I'll be going up soon to discuss possible new treatments I have said that I would not take anything if it contained ribavirin again.
30. There was a big gap between my first and second treatments but I do not remember why. I was told after I finished the interferon in 1998 that although there was a possibility of re-treatment on interferon and ribavirin, it was not available at the time. This can be seen within the aforementioned exhibit **WITN2131008**. I was not aware of any other

ANONYMOUS

treatments that I thought I should have been given. I now have fibre scans of my liver instead of biopsies.

31. In terms of any obstacles to treatment or obstructions, I feel as if I am always having to go through my entire medical history from the point of infection each time anyone new is involved in my care. Doctors always wear gloves and there have been instances such as where a young doctor has read my notes and asked me if she should have been wearing gloves. I recall that before my first treatment I had a biopsy of my liver. This is one of 4 or 5 that I have had. I had to take holidays for the biopsies as I didn't live in Glasgow and had to travel up for them. I recall a nurse saying that they couldn't take me one day even though I'd already taken time off.

32. The only support I received was the Dr Tang I have mentioned as well as medication. The nurses that are there when you are getting interferon treatment are great. I recall there was a nurse called Liz Little and she saw me through my second treatment and she was very understanding. I recall telling [GRO-D] about my hair loss and he sort of brushed me off, whereas a nurse said that hair loss was a common symptom. I do believe I would have benefited from counselling even now.

Section 7. Financial Assistance

33. In terms of financial assistance, I took early retirement in 2013 and I was in the lower income bracket. I took early retirement because I was going to be made redundant. I got £189 per month from Caxton. I do believe at one stage I got £315 a month when the Scottish government took over. There was a girl at the Caxton Foundation who was very helpful to me. I recall at a meeting about the financial review group, I was told that they would not be able to help with travel costs.

34. In terms of the Skipton Fund, I did receive £20,000 in 2004. I found this to be a relatively easy process, other than the sense I had from the doctor who had filled in the form that he did not see why I should be

ANONYMOUS

receiving financial assistance when those who had contracted hepatitis C through drug use did not.

35. I received a lump sum of £30,000 in 2015. This was from the Scottish government, as I believe this followed through from the Skipton fund.

36. I am now receiving £1575 per month from the Scottish Infected Blood Support Scheme. Another amount was also backdated from September 2018; I am unsure exactly how much this was. I found the application form to be straightforward. I also marked myself as severe.

37. I have found the financial support I have received to be sufficient and it has been a great help to me so far.

Section 8. Other Issues

My experience of the Penrose Inquiry

38. I was a core participant in the Penrose Inquiry and I felt that it was a waste of time and a waste of taxpayer money. I felt the Inquiry was biased against the affected and infected from the start and I did not feel that the experiences of those who had been infected were taken seriously by the Inquiry. I particularly recall that one of the things that was said was that every minute a consultant was there, was another minute he was away from the NHS and every bit of money spent was money away from the NHS. I did not feel listened to and I do not believe that the Inquiry really answered any of the questions I had as an infected person.

36. I confirm I would like my statement to be an anonymous.

Statement of Truth

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

ANONYMOUS

Signed

GRO-B

Dated

25/4/19.