

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2840001

Exhibits: None

Dated: 4th February 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 the 4th February 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B 1957. My address is known to the Inquiry. I am currently working three days a week and living alone after the breakdown of my marriage due to hepatitis C. I intend to speak about my infection of hepatitis C, in particular the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family.

Section 2. How Infected

2. I was in a relationship with my former partner [GRO-B: P] date of birth [GRO-B] 1955. I had a daughter with [P]. He had a blood transfusion at Edinburgh Royal infirmary, Lauriston Place, on the 15th January 1975 after a road traffic accident. He was infected and he did not know he was infected for many years. Our relationship broke down, due to violence in the relationship which came about due to mental health issues which were out of character for [P]. I do wonder now if the mental health issues were related to the hepatitis C. My daughter, [GRO-B] was born in 1986 and the relationship parted ways in 1993, now we no longer speak. Years passed and [P] phoned my daughter in February 2010. He told her that he had hepatitis C and that if I was still having physical problems, that I had done previously, I should probably go and get tested. My health at the time was quite poor, I had had a number of mysterious problems over the years, trouble with arthritis, depression, anxiety and bad muscle pain. There were days I could not get out of bed, I was so sore. After I gave birth to [GRO-B], I was really ill and after investigations the hospital advised me that I had an enlarged gall bladder. On reflection, I don't think that is what it was, I think it might have been the hepatitis C. Over the years, I would have mysterious illnesses including in 2004 when I developed water blisters, all over my body which made it look like I've been bitten all over. I became swollen and went to hospital in [GRO-B] where I was treated with steroid injections to reduce the swelling. It looked like someone had dipped me in hot fat, it was very frightening but there was no conclusion as to why this had happened. After [P] phoned in 2010, I called my GP to get tested. My husband at the time [GRO-B], dismissed this and said it would be fine I was probably not infected. I still did get tested though and a couple of weeks later, I came home from work to an answer machine message from my GP's practice nurse saying *"I'm sorry pet, the test was positive you, have hepatitis C, there is no cure for this get in touch on Monday"*. I got this message on a Friday night and spent Friday to Monday convinced I was going to die. I was in a terrible state all weekend. On the Monday, my GP sent the results to the Edinburgh Royal infirmary, who confirmed I was

positive. They then contacted me separately saying the results were negative. They then contacted me again and said I was positive and I didn't know whether I was coming going. I instantly asked at that point, to be transferred to Ninewells hospital, Dundee, as I had no faith in the Royal infirmary, Edinburgh at this point. I went to Dundee and they confirmed the diagnosis. They gave me the options of treatment and advised me on practical information about the illness. They gave me the options and warned me that this could develop into liver cancer. It was explained to me as being like a sleeping dragon, when it hits you, it really hits you. When I was diagnosed, I definitely wanted the treatment.

3. Yes, adequate information was given by the hospital but not by the GP. The message from the nurse was disgraceful. I do not think my practice nurse that left the telephone message did so with malice. I think it is due to lack of knowledge and training. Further to this, the GP had no idea what hepatitis C was and they weren't able to give me practical information either. I'm registered with GRO-B Although my GP tried to be supportive, the lack of knowledge and experience in Hepatitis C was obvious. At one point, my GP tried to prescribe me Iron for intense fatigue. I was aware through Ninewells that I should not take this as I was warned about Iron in my diet. I instructed my GP to call the specialist nurse Jan Tate who informed under no circumstances should I take Iron. As I said, there was a lack of knowledge about Hepatitis C.
4. When I received that telephone message from my practice nurse, I was in a state of shock, I spent the whole of Friday to Monday on a computer looking up hepatitis on various different websites. At this point my ex-partner didn't know how he had contracted the infection either, but the doctor at the hospital did ask him if he had a blood transfusion in the past. It was worked out from there that this is where the infection had come from. The information was adequate at the hospital but nowhere else.

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5. Yes, I have views on how the results were expressed, they left me a voicemail to tell me I'd had this on a Friday evening. It was heartless and extremely frightening.
6. I brought up a lot of questions at the hospital because at time, I had six grandchildren and I had a lot of input with their upbringing. I had three of them living with me at the time so I was worried about their welfare. One grandchild cut himself on a razor in the bathroom and I was extremely scared I was going to infect him. The doctor at Ninewells reassured me and told me that because the cut was gushing with blood there was nothing infectious on the razor as it would have probably flowed away. GRO-B
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- while I was undergoing the treatment, which I did several months later.

Section 3. Other Infections

7. No I've not contracted anything else other than hepatitis C.

Section 4. Consent

8. No, I have not been treated or tested against my knowledge but how would I know if that had occurred.
9. No I don't believe I've been treated without my consent.
10. No I don't believe I've ever been treated or tested without being given full or adequate information.
11. No, I don't believe I've been tested for research. I did rip up my medical records after the first time, this was agreed with SIBSS though, because I'd had enough of it.

Section 5. Impact

12. I married [GRO-B] and my relationship was good. When I found out I was hepatitis C positive, [GRO-B] attitude changed towards me completely. When I told him I was infected, his response was "*How did you get a junkie's disease?*" He became instantly distant. We no longer had sexual relations, he couldn't handle my anxieties, my depression and I couldn't socialise anymore. We didn't go out and didn't socialise together at all from then on. [GRO-B] refused to get tested for a long time until the doctors told me I was clear of hepatitis C. On my final appointment, he finally agreed to be tested himself and he tested negative. Physically, I had really bad arthritis, if I got down on the floor it took me ages to get back up again, I had lots of pains and I could not explain them. I had a lack of confidence and I have never been able to have an intimate relationship since then.
13. I've got a lot of problems with pains in my arms and depression, anxiety, skin problems and issues with my eyes which breakout and swell up at points. I have migraines and I experience a lot of joint pains as well now. My memory is short, [GRO-B]
[GRO-B] and I had to explain myself at work during the illness for things like this and a suicide attempt in 2012. I was emotional all the time, I felt like I was living with a secret that I didn't want to discuss. The infection has such a stigma around it, obviously I had to tell work, the depression, anxiety and panic attacks haunt me to this very day though. I still can't sleep; I only manage around 3 hours a night. I was absent from work for a long time in 2012 and [GRO-B] couldn't take it anymore and he left me. That left me in debt, scared I was going to lose the house and led me to attempt suicide. I took an overdose and it was only because my daughter found me that I am alive today. [GRO-B] couldn't take it, I wasn't socialising, I wouldn't go on work nights out and that was it for him. I lived in the country at the time and I felt very lonely and it all led up to the suicide attempt. It meant for a short while, I had to register myself as a vulnerable adult

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The most difficult aspect of this was all my children and all my grandchildren had to be tested for hepatitis C. All of them were negative but it took a very long time to confirm this result which was incredibly stressful for all of us, that was horrendous. There was still no offer of psychological support or anything even then.

14. I went onto Interferon and Ribavirin in 2010, it was a 6-month course and it was horrific. I went through it all under the care of Ninewells hospital and I did clear the virus at the 6-month mark. They stopped the treatment then I was discharged. There were no follow-up appointments, no scans or anything like that. Years later I did request a follow up appointment as I was not feeling well at all but I still tested negative for the virus and there has been no scans on my liver. I am grateful for the treatments but it does leave you with a lot of issues, for me with arthritis and anxiety. During the treatment all I could do was lie in bed, I moved up to the attic and I couldn't leave it for the whole six months practically. I couldn't speak to people, I was shouting at everyone, I had no energy, I couldn't do anything. My family used to visit every Sunday for Sunday dinner, that all stopped after I started treatment.

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but the other side is that they didn't visit me as much anymore and we are now more distant. My hair thinned, I did have a bald patch but it was very thin mainly. My skin was peeling off, I felt like I had bad sunburn, I remember I asked GRO-B to put cream on my back when the peeling was very bad and he refused because he thought he would catch the hepatitis C. He really believed that I had a junkie's disease. I ended up having to hire a professional masseuse to help me to get some relief. I lost about 2 and a half stone in total. Now I can only sleep about 3 hours a night, otherwise I am up reading, listening to music, doing yoga and doing anything to try and take my mind off everything. My mind just buzzes all the time, I think about my marriage,

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my house, my family, everything. I lost a promotion during this entire period as well which I feel quite bitter about.

15. No, I was seen straightaway, there were no obstacles.
16. I was never offered anything else, I'm not aware of any other treatments at the time, I believe there are improved treatments now but they did not exist in 2010.
17. No, I filled in the medical forms which stated I had hepatitis C but it was never discussed with any other medical professionals, they treated me normally.
18. I was legally separated in 2012. I'm not divorced just now though, I have no contact with [GRO-B] anymore which has devastated me. I loved [GRO-B] deeply, he was my life. My daughters, [GRO-B] and [GRO-B] have been fine, my son, [GRO-B] on the other hand has kept his distance. He has just had a new baby and I feel they are very suspicious with me. They always check how I wash my hands, have I done this, or have I done that, I never had this before and it makes me feel dirty. The hardest part of this was when they all had to be tested. I remember when I finally found out that all my children and grandchildren were all negative, when the final result came through, I was on holiday and I sat on the beach and I just cried and cried. I felt worse for them than me, it was awful knowing that they might have been infected by their granny. I don't know the current status of [P] health. I have no contact with him and cannot comment further. I told a few other close friends but no one else, my close friends were all really supportive.
19. There were no educational affects that apply.
20. I work for [GRO-B]
[GRO-B] I put in for a promotion a couple of years ago but because I was off for so long, I

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missed the interview. I can't do that now; I would have liked to have done this though. The role was a [GRO-B] which is a senior version of what I do now. I had to be off for the full six months though, I had no choice, I still take a lot of sick days now. I went back after the original six months to avoid going onto half pay, when I did, I instantly noticed that my concentration was nowhere near what it had been previously. I suddenly noticed when we had a meeting, I was put on the back of the rota, so things to discuss for me did not come up until the end of the meetings. My boss, who did know about the hepatitis C, said in front of everyone that she had done this deliberately so maybe I would try and stay awake for the full meeting. I felt so belittled, she knew I was struggling, it was very unkind. When I first went off work my colleagues wanted to get me a 'get well soon' card, but they didn't know details of my illness. That same boss told them "*No she doesn't want that*" which of course makes the people wonder why. Now I am back to work, but I can't concentrate in full. I have no energy and I've have had to go down to 3 days. I go to work, I come home and I go straight to bed because I'm so exhausted. It's a very physical job, which I can do but I need time to consider different scenarios which is my biggest problem, my memory. I have now in February 2019 have made the very difficult decision, that I will be taking early retirement as I am no longer able to continue with the job as [GRO-B] I have spoken with my employer and I will be finishing work in June 2019. This is an extremely emotional and difficult decision because I really love what I do [GRO-B]

21. Financially, it was very bad at first, I couldn't afford the house I was living in. Since I've been awarded the Scottish Infected Blood Support Scheme money that has helped. I've managed to pay a lot of the mortgage and I cut the days out at work. I have no problems with insurance, I've had my insurance a long time though. It was a godsend; I don't know where I would be without it.

Section 6. Treatment/Care/Support

22. I've had no psychological support. I've tried very hard to get this, it's been my issue. It is something I don't speak about at work and I don't want to lose my job, further to what happened with my suicide attempt in 2012. I've been asked by the doctor if I'm suicidal and I have said no, so as a result I have to wait on a waiting list. There has never been any support for the hepatitis C itself, I was just left to go through everything on my own. I am hearing for the first time today that there is psychological support that is being offered during the Inquiry. I was not aware of this and I would be grateful to speak with someone if the opportunity arises. The treatment is such a horrendous treatment; support should have been vital. I remember I was driving to work and I remember this day, having to pull over onto the hard shoulder because I couldn't see through tears. Counselling for my marriage to help [GRO-B] understand what I had may have saved it, but he shut down and I shut down.

Section 7. Financial Assistance

23. One of the support sites told me about the Skipton fund which is how I got in touch with them.
24. Ultimately, I received £50,000 from the Scottish Infected Blood Support Scheme and I have been awarded £1500 every month for three years.
25. I filled out the form, I phoned SIBSS a few times, the people on the phone were very supportive and talked me through everything. It was all accepted, the doctors completed a lot of the information at Ninewells. However, the first time I applied, this was refused and I had to wait many years until [P] applied for support before I was allowed to apply.
26. Yes, I was rejected originally because my ex-partner [P] had not applied for financial assistance. He was the one who had infected me therefore, in order for my application to be successful when it was

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Skipton, [P] had to declare what had happened because this was the reason I was infected. For as long as he chose not to receive help, I was not eligible for any despite our circumstances. He did eventually apply for help himself though, when I found this out I applied and was successful. I will point out here though that it was me finding out myself through our daughter, no one contacted me and I would have missed this had it never been raised again. It shouldn't be like that. It was this point where I was able to get the documents together to prove everything, which I did, by which point Skipton was no longer in existence and it was replaced with SIBSS.

27. The precondition that was applied was that [P] had to decide to apply and be granted money before I would even be considered. Despite the fund being aware of me, they didn't even try to contact me later on when this occurred and if [P] had never applied I would have been left to struggle.
28. I have no other comments at the moment to make about financial assistance, I was grateful for what I got which helped in a time I really needed it.

Section 8. Other Issues

29. I've no other issues to raise for the Inquiry, I understand Thompsons are recovering my medical records for which I'll be given an opportunity to review.
30. I would like to remain anonymous for the purposes of the Inquiry as I feel anxious to have to keep going through this over and over.

Statement of Truth

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

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Signed

GRO-B

Dated

21-3-19