

Witness Name: GRO-B

Statement No: WITN2838001

Exhibits: None

Dated: 11th December 2018

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 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 1948. My address is known to the Inquiry. I am currently living alone and retired. I intend to speak about my partner GRO-B: P and his infection with hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together. I wish to remain anonymous for the statement.

Section 2. How Affected

2. [P] was involved in an incident in 1983, which left him with a very noticeable scar on his abdomen. He was admitted to the Old Royal Infirmary in Lauriston Place, Edinburgh where he was operated on and received a large blood transfusion. [P] and I entered into a relationship from the year 2000 until his death, so this took place before I knew him.
3. He was infected by receiving this blood transfusion with hepatitis C. [P] passed away in [GRO-B] 2018.
4. [P] received a blood transfusion in 1983, I do not know how many pints of blood he received. It was due to an incident that occurred in Edinburgh. I believe he was attacked by a stranger in the street.
5. [P] had a massive scar on his stomach and I believe the doctors had to operate quickly to save him. This led to the blood transfusion. I do not know how many pints he received.
6. [P] was treated at the old Royal Infirmary, Lauriston Place, Edinburgh and the new hospital in Little France, Edinburgh, up until his death. [P] was registered with several General Practitioners in Edinburgh over the years. One of them was a GP Surgery on [GRO-B]
[GRO-B]
7. [P] received the infected transfusion in 1983. I am unclear about the details of this transfusion because I did not meet him until the year 2000. When I knew him he was already infected. I believe the cause of his injury was an incident when he was attacked by a stranger in the street and [GRO-B]

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8. I don't know when [P] found out he was infected or details around this however, what I do know, is around the time he did find out in the early 1990s, this was when his marriage broke up.
9. I don't know what information or advice was provided to [P] about the risk of being exposed to infection before and/or after he received the transfusion.
10. I don't know what information was provided to [P] about the infection when he was diagnosed and I don't know who provided that information.
11. I don't know if adequate information was provided to understand and manage the infection. This is unknown to me.
12. I can't answer the question that information should have been provided earlier to [P] because I don't know when he found out the details around the infection itself.
13. I don't have any views about how the results of the tests and information about the infection was communicated to [P] as I was not around when this happened.
14. I don't know what information was provided to [P] about the risks of others being infected as a result of the infection, he has never discussed this with me.

Section 3. Other Infections

15. I don't know the answer to this, there were no letters about variant CJD, so I'm not aware of any other infections other than hepatitis C itself.

Section 4. Consent

16. I don't know if he was treated or tested without his knowledge, I can't imagine he was in a fit state when he needed the transfusion to discuss

matters, so I can't answer fully.

17. I do believe he was probably too ill to give consent for the transfusion however if he hadn't received the transfusion he would have probably died.
18. [P] wasn't given full and adequate information about the treatment for the hepatitis C. He had a horrendous course of treatment which lasted 6 months during which time he suffered a number of side effects including blinding headaches, losing his hair and itchy skin rashes and worse of all he would collapse at random times, even when crossing the road. The nurse at the ERI who administered the treatment was a Sister [GRO-B] who was completely uninterested in the effects of the treatment although I asked her if it was normal for him to collapse. The treatment didn't cure the hepatitis and his health was impaired from this point. He developed type 1 diabetes and I believe that this was related to the hepatitis C infection and to the treatment with Interferon and Ribavirin as developing type 1 diabetes over the age of 50 is very unusual.
19. I don't think he was treated for the purposes of research.

Section 5. Impact

20. [P] was depressed. He was also embarrassed, those who knew him were fine, but there was always a concern that everybody thought he was a junkie. He was diagnosed with depression in 2005 and he was on antidepressants. [P] was in pretty good health when I met him in 2000 and he was still working, his health began to deteriorate in 2004/2005. He suddenly became very tired all the time and his stomach was swollen.
21. Diabetes type 1 from either infection or from the Interferon and the Ribavirin or possibly both. It is very unusual to get diabetes type 1 over the age of 50. He had to get the maximum amount of insulin to treat the diabetes. He had regular hypos both before diagnosis and after when he

would become confused and collapse and then there would be a danger that he would slip into a coma. His medication was adjusted and eventually he found a regime that suited him and he had hypos less often. He had permanently bruised fingers from pricking them to get blood and his torso was also covered in bruises from the injections he had to give himself. The bruising combined with his swollen stomach embarrassed him too much to go swimming. The diabetic unit at the ERI were quite helpful, the only problem I have with the unit is that it was next to the liver unit at the ERI but the two departments did not communicate with each other, so for example when [P] was called in for a scan or a procedure, which involved a period of abstaining from food, he should have been asked to come in first thing in the morning as it is dangerous to go without regular food for a diabetic but they never got the timing right and it always had to be changed.

22. [P] always hoped he would be cured. I had faith as well although he became increasingly tired and exhausted after 2005. He became unable to work and had endless problems with the benefit agencies. He was constantly having his benefits stopped and the benefits people treated him with a complete lack of compassion and with disdain. He would have to trek back and forward to appeal after appeal with the benefits department. His benefits would be stopped for weeks at a time until finally he was accepted on the Skipton fund and an advocate from the Caxton foundation came and spoke for him. Once the Caxton foundation became involved, the troubles with the benefits agencies came to an end and then [P] started to receive some money from the Skipton fund which made a huge difference financially and psychologically.

23. I can't remember the timeline for the new drug that became available, but this was a lot better and it did clear him of hepatitis C. But by the time he was declared clear, he was stage 2 and had cirrhosis of the liver. Not long after he was declared clear of hepatitis C, he was tested for a liver transplant. This was a fairly stressful procedure when the doctors would meet and see if the patient was a suitable candidate for a liver transplant.

It did feel as if you had to win a place. He was successful. He had a strong constitution when they said he was eligible for a transplant, even though he did not have the physical strength or endurance that he had before he had become ill. [P] never complained, he passed the tests and he was put on the waiting list. A liver was found and he was given a transplant but 5 days later, this liver failed. Luckily another liver was found in time and he had a second transplant. He was told that his body would not be able to take a third transplant.

24. He got the liver in June 2016 and he got a new lease of life. He was naturally quite a cheerful and sociable person and was able to do ordinary things like gardening, making bread, cooking, visiting people and going to the cinema. In Christmas 2017, he started to deteriorate again, his stomach swelled up again and he often fell asleep in the day and would go to bed early. He withdrew into himself. He kept going into hospital for tests and scans and gastroscopies and several liver biopsies which were very painful. I would ask him if he would like me to come and he would say not to bother, but I wish now that I had gone with him so that I would have known more about what was going on. We had booked our first holiday in years in [GRO-B] and we went to Italy. It would have been a lovely holiday but [P] was exhausted and couldn't walk far. He was very quiet. I noticed at that point he started to go yellow but I didn't say anything because I thought we were in Italy, what could we do? He didn't like a fuss. We got back to Edinburgh and he was really yellow at this point. He had another appointment at the ERI. The hospital kept him in and he deteriorated rapidly. His kidneys started to fail but at one point he was allowed home as I had learnt how to administer his food through a nasal tube, but his condition deteriorated again and he had to return to hospital. Things got worse and worse and they tested him again for another transplant and the doctors decided that he was going to go on the transplant list again. He was delighted with this information, but he died 2 days later, 3 weeks after our holiday. The NHS had changed the system of transplants. It is now not confined within Scotland and is UK wide and instead of the person with the most acute need of transplant

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being on the top of the list, they just go with a match from donor to patient. P was sleeping a lot before he died. I went in on Sunday the GRO-B and then I got a phone call from him in the middle of the night and all I could hear was his rasping breath. I called the nurse who told me he was ok. Then he called me again and once again couldn't speak so I phoned the nurse again. I heard nothing and then the hospital phoned me and told me that P had developed pneumonia and had had a massive cardiac arrest. They had resuscitated him and he was in critical care. I went into the hospital. P recognised me but he was in an agitated state and very uncomfortable. I asked the doctor to please give him a sedative but she refused and he was kept alive until the evening when they finally sedated him. He died at GRO-B on Monday GRO-B 2018.

25. P received interferon and ribavirin treatment. This treatment had terrible side effects. He suffered severe headaches, irritating and unsightly rashes and he kept collapsing. He collapsed whilst crossing the road one day. He felt awful and this was when the diabetes type 1 was diagnosed. I cannot recall the exact dates of this.
26. Into 2006 we did have to wait awhile which was quite nail biting. We were seen but we thought we would have been seen earlier.
27. Not that I'm aware of.
28. After the first course of treatment he was extremely fatigued and didn't look well at all. He developed a strange eczema and his hair started to fall out, there were a lot of side-effects to the treatment and it didn't cure him. He would collapse constantly, he always had a severe headache, his stomach was very swollen and he was extremely depressed. It reduced his quality of life. He was unable to work from the treatment and the illness.
29. P's teeth were terrible. He got free dental treatment. He was quite a healthy guy apart from that. He had an amazing immune system and he

never got colds and illnesses until this. He came from a long lived family with no history of diabetes type 1. After he developed diabetes, he had permanently bruised fingers where he had to prick them to draw blood and massive bruises on his torso where he had to inject himself daily. Doctors would take precautions and put gloves on and things like this, which is fair enough, but it probably didn't feel nice for P though.

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GRO-C

GRO-C

, but he

was not a complaining man. He never complained even when he was in severe pain, which was often. One of the worst side effects of the anti-rejection drugs he had to take after his transplant was a lack of control over his bowels. This restricted his social life and caused him extreme humiliation and embarrassment.

31. I think I am still processing everything, it's been quite stressful over the years and I'm still in the early stages of grieving. It was very hard for many years with the worry about his liver and whether or not he would get a transplant. I kept his illness a secret because of the stigma. He was very ill towards the end and he just gradually was unable to do anything. He was 63 years old when he died and could have expected to live another 20 years as his family is long-lived and he was a healthy man before he was infected. I was constantly worried about him, not just his liver but also his diabetes. He could have slipped into a coma very easily. I bought him a medical bracelet which saved him a few times. People would see him in the street when he was having a hypo and assume he was drunk, but when the bracelet was noticed he was either helped home or on one occasion taken to hospital. Certainly his family didn't like

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to talk about his illness because of the stigma. He didn't like people to know and I didn't tell people either.

32. GRO-C
GRO-C. He found that some acquaintances assumed he was on drugs. I recall that he went to the local pub one night and this guy in the pub found out that he had hepatitis C and was telling people that he was a junkie. P was very angry and upset about this and stopped going to that pub as he was embarrassed.

33. I was concerned about catching hepatitis C myself and I was careful about hygiene.

34. I think he felt dirty and bad, people didn't want to touch him in case they got infected. There was the fear of what was going to happen to him and how his illness would progress. I know someone else who died from hepatitis C in an unrelated matter and their death was not pleasant. That was the main fear as well for P as he was aware of this as well.

35. There was a dramatic impact on P's life and work. He had several jobs over the years and in the 1980s and 1990s he had a highly skilled and well paid job as a GRO-B
GRO-B
GRO-B when I met him but eventually he got too ill to work at all.

36. I was affected in that I became the main breadwinner and I suffered depression and anxiety from the strain.

37. The financial impact was big, we didn't have any money, which meant scrimping and saving. For example, we didn't have a car, we didn't go on holiday and we didn't eat out. I had to keep him. I paid for everything, he stayed wherever I was and I supported him. I would help him until his benefits were paid but there was a constant back and forward with the benefits office. They would constantly try to cancel his claim which

caused a lot of trouble, so he did need support all the time. He would pay me back when he could, he didn't owe me any money in the end. I can remember when we finally went on holiday this last GRO-B that travel insurance was an issue and it was more expensive.

Section 6. Treatment/Care/Support

38. P was offered counselling and he did do this which I think helped him. I was not offered counselling and I think I should have been as it was a heavy burden for me, not that I was aware at the time but later on, I felt the full effect. P should have had more counselling around the liver transplant, he felt very guilty when he had the transplant, particularly because it was a young boy whose liver he received. He felt bad about that.

Section 7. Financial Assistance

39. I can't recall details, it was either the hospital or the counsellor who gave him details of the Skipton fund and once he obtained proof of his infection from a blood transfusion, he was able to get assistance. He did need an advocate from the Caxton foundation to get support with the benefit tribunal.

40. I am not sure on the details of this, I would have to contact the Skipton Fund to be very clear. I will try asking him for details of money they gave and when and provide this to the Inquiry later on. He received a lump sum from Skipton and the Scottish government. I think in all it was worth about £60,000 in different lots. I would have to clarify. So far I have been unable to contact them to obtain details.

41. It took a while to get the Skipton Fund sorted. He got all his evidence ready to show that he was eligible which took a while but once he had done this it made a difference that someone was listening to him.

42. [P] had to prove he had tainted blood; it took a while to prove this. He had to see his GP and he went to the blood transfusion unit and was able to find evidence. He was extremely lucky as I'm aware that some people have been unable to recover this evidence as their records have been destroyed.
43. I'm not sure I guess the precondition that was applied was that he had to prove his infected situation.
44. The Scottish Government were good about taking over and making sure that people got payments up front, we finally got money; it was a nightmare before that. Since his death, I have been granted the pension he had as I come under the definition of a common-law wife. I receive two thirds of this pension. I had to apply for it. It was fairly straightforward for myself though, I phoned them up, e-mailed over a death certificate and passport. After that they took care of everything.

Section 8. Other Issues

45. [P] was quite active with the Infected Blood Forum. He was in correspondence with [GRO-B: F] and he did some research but I cannot find this research and I don't know what has happened to it. Unfortunately, [F] is quite unwell now. It's been a long rollercoaster of illness, horrible, we didn't know what was going to happen he just became worse and worse and there was the stigma and being treated so badly by the benefits agencies. Initially he was afraid to tell people. Although he was a sociable person he was a very private person and he suffered enormously and suffered a lot from the humiliation and from the often severe physical pain. It was a cruel illness.

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Statement of Truth

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

Signed

GRO-B

Dated 20.2.19