

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN2252001

Exhibits: None

Dated: 13th 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 14th 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 and my address is GRO-B
GRO-B. I am GRO-B
husband. I intend to speak about my wife's experience of being infected with hepatitis C. In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.
2. My wife normally uses her middle name GRO-B: W rather than her first name, W. My wife contracted hepatitis C when she received a blood transfusion following a miscarriage in 1985.

Section 2. How Affected

3. In October 1985, my wife was six months pregnant and she started to miscarry. She was taken to the maternity hospital in Dunfermline. I was not allowed in with her, and she lost the baby. She lost a lot of blood. When I came in to see her, they were giving her a

ANONYMOUS

transfusion. We just held hands and didn't say too much. I saw her again the next morning and she was very ill. She had been ill but stable the night before. She had experienced some sort of trauma through the night. I think that she experienced uncontrollable shaking. The nurse had called the doctor then. I do not know how many units of blood she was given following her miscarriage, but it was definitely more than one. When I saw her in the morning she had recovered from the trauma, but was still very ill. She could hardly speak. I then had to tell her that our baby had died. We recovered from that. Life goes on. Her health recovered afterwards. She didn't have any more illnesses than anyone else. It was 15 years later that the hepatitis C symptoms started. By then, we already had another daughter and had been focusing on her. It was in 2010 that we found out that she had hepatitis C, but nobody knew where it had come from. Dr Bhattacharyya was a specialist in haematology at Kirkcaldy Victoria Hospital. He scared my wife and accused her of being a drug addict. He offended her. It was unnecessary. On hindsight, he was trying to find reasons for her hepatitis C. Hepatitis C feels like it is really not there until someone tells you that you have it. Five years later, in 2015, new treatments started coming out.

4. w hepatitis C was severe. She had a lot of problems, more so after her treatment, but even before the treatment she imagined that there were these little creatures in her blood and it freaked her out. She had nightmares and disrupted sleep patterns. She couldn't sleep properly and the stigma was really bad. She was paranoid about bleeding in front of anyone, especially our children and grandchildren. She didn't want to go anywhere. In 1987 or 1988, she started having severe migraines and had treatment for them, but they were never cured and are still ongoing. I don't know if these are linked to her hepatitis C. She also had problems with her joints and hips, arms, knees and ankles. This came from her Interferon treatment. She became very ill to the point where she was advised to stop the treatment when she only had four more weeks to go, and she kept going. I worried a lot. Her choice was to keep going with the treatment, but I thought that she was dying. Since then, she has never recovered. She lost her hair and came out in rashes. It was horrible. She experienced a terrible loss of memory. All this happened during her treatment.
5. I don't know which particular blood products my wife received, I don't know which particular kind of blood it was. We tried to get information, but had no hospital records as

ANONYMOUS

they had been destroyed. We only found a discharge record from the hospital which gave her blood count at the time that we lost our baby. Her blood count was terribly low, but she did discharge herself because she was terrified due to the trauma. The pain of losing a baby never goes away.

6. My wife was treated at Dunfermline Maternity Hospital, which does not exist anymore. That is why she was unable to obtain her medical records. We tried to find out the name of the doctor who treated her, but couldn't. Her discharge letter had no information about this matter and the area where the name of the treatment should have been had been left blank. I suspect that they knew exactly why she was not well and that is why they did that. Afterwards, she was treated at Victoria Hospital in Kirkcaldy. It was Dr Bhattacharyya who interviewed her. Her hepatitis C treatment took place in at Queen Margaret Hospital two years ago. She was treated by a clinical nurse. She started treatment in November 2015, which is when the treatment commenced and it lasted until March 2017. The treatment lasted for 16 weeks. Our Christmas that year was a nightmare, it was non-existent. GRO-B
GRO-B. Thus, I do not really have an income. I have a small pension, but she shouldn't be working, she is in pain constantly. I think that she has PTSD. She won't go to hospital for any reason. She fell and we thought that she had broken her ankle, but she still refused to go to hospital. She will not even go to her GP, something really bad would have to happen to make her go. We have lost trust in the whole system. I worry that she is terrified of hospitals in case she suffers some serious illness that requires treatment immediately.
7. My wife received a blood transfusion after losing our baby in October 1985.
- No information about the risk of being exposed to infection as a result of the blood transfusion was given to her or to me. She had just lost a baby and she wouldn't have understood, she would just have accepted the transfusion. But she was never asked or explained anything. It was a matter of either receiving the transfusion or bleeding to death.
8. My haemophiliac friend got HIV from factor 8 and his whole family rejected him. He was not allowed to see or touch his two children anymore. He ended up hanging himself. He was given a house because of his illness and he hung himself. GRO-B. His name was GRO-B. Haemophiliacs were delighted to be able to inject themselves factor 8,

ANONYMOUS

but little did they know that it was infected. However, my wife only has hepatitis and no other viruses such as HIV or Hepatitis B.

9. She found out that she had hepatitis C because I had been ill for a long time and I went to see the doctor, who told me that I had HIV. This meant that my wife had to get tested, and that is how she found out that she had hepatitis C. We got tested together and got the results from the GP. I was found out not to have HIV in the end. At the time, the treatment for hepatitis C was a long process, it might have taken a year to complete. The GP advised that progress was being made and to wait for a new treatment which came out sometime later. She had hepatitis C type 3 and required a different treatment. Our GP is GRO-B and this happened in 2010, a few weeks after she got tested. She was tested at the Infected Blood Clinic in Kirkcaldy, at Victoria Hospital.
10. No information was really provided to us about the hepatitis C infection, not even a prognosis, because just because you have hepatitis C doesn't mean that you are going to die from it.
11. I don't think that adequate information was provided to understand and manage the infection. We were just told to abstain from alcohol, nothing else. She was accused of being a drug addict and not told that her infection might have been a clinical thing. She was not told too much about it even when she was already receiving treatment. We had to learn about it ourselves through research on the Internet. Countries in Europe other than the UK had been affected by contaminated blood and there was a lot to read.
12. I think that the information should have been provided earlier. Had my wife known how evil the treatment was and how it affected her, she would never have taken it. She was told that taking the treatment would be like having the flu and it was really like having chemotherapy. It was horrendous and the repercussions were even worse. She had aches and pains that never left her and it just got worse. She got joint pain. We think that they stole our future. We had plans for later on in life. I cannot even find the words. We live from day to day now, we don't dream about the future anymore. And we are getting older, worrying about death and about whether the illness is going to manifest itself in a few years' time, that is, whether it might come back as that is still a possibility because you don't ever get cured of hepatitis C. They just leave you with a count so small that it

ANONYMOUS

seems like the infection is not there anymore, but it is. [W] still feels like she has little bugs in her blood, they are still there and she still has nightmares and sleepless nights.

13. My view about how the treatment was communicated to us is, for starters that there was some kind of cover-up. There was a lack of details in my wife's discharge letter. If anyone knew that it was possible that she could have been infected, they should have informed patients. We were told that my wife had hepatitis C in a very blunt manner. The virus attacks you liver. [W] was stunned when she found out. She went in to the clinician herself and came out crying. She said: "You won't believe what that bastard said to me, he called me a junkie and asked when I had my last fix." It was Dr Bhattacharyya who said these things to her. She was never ever told that she had contracted hepatitis C because of the transfusion. She started her treatment in November 2015. The people treating her never even once mentioned a thing about the contaminated blood, just asked where she might have picked up the virus. The virus could have been acquired through any blood contact, but you can never know when. We found out about infected blood by having a look on the internet. We found ourselves and it took a year for the Skipton Panel to accept that it was the most likely cause of my wife's hepatitis C. My wife has a friend who, when my wife was miscarrying, looked after her daughter and my wife had confided in her friend about the blood transfusion. I was her friend's testimony and my own testimony that convinced the Skipton Panel.
14. We were only given information about the risks of others being infected as a result of the infection after my wife's treatment. That time was a period of denial. You don't tell anybody that you have hepatitis C. We knew from our own research about the risks of others becoming infected. We knew that hepatitis C can be passed on, hence the problems with our family, friends and grandchildren. Our family were understanding. No nurse, doctor or clinician explained anything about hepatitis C other than she had it and not to drink alcohol.

Section 3. Other Infections

15. I don't believe that my wife received any infection or infections other hepatitis C as a result of being given infected blood products.

ANONYMOUS

Section 4. Consent

16. Nobody knew about infected blood at the time when my wife received the transfusion so no doctor or nurse could have said anything about it and my wife could not have made a conscious decision anyway because she had lost a lot of blood.
17. I do not know whether or not my wife was treated for the purposes of research. I know that people were deliberately infected with HCV back in the 70s and 60s. I do think that they might have given her blood knowing that there was a risk. I blame the Blood Transfusion Service and the Government Health Department for not disclosing this. I don't blame individual doctors and nurses. The Government found cheap blood, bought it and didn't care about anybody else. The source of the blood was prisoners in America, which is an indicative of the quality of the blood as many of them must have been drug addicts. Some blood might have also come from India where hepatitis C is common.

Section 5. Impact

18. Becoming infected with hepatitis C had a huge impact on my wife.
19. The mental and physical effects of being infected with hepatitis C before the treatment were that my wife experienced aches and pains all the time, but it was after the treatment when things were horrible. She had pains in her joints and in her shoulder that were inexplicable. She had pains in her knees and ankles and they switched from one place to the next. She felt like she had little creatures rushing about in her blood and attacking her joints. It was a constant thing and still is. Her pains move about to different joints. She takes a lot of painkillers. She takes Paracetamol and Ibuprofen every day and I think she takes too much.
20. I don't think any other medical complications that have not already been discussed resulted from the infection. I do not know whether the migraines that she developed shortly after the transfusion, which are still ongoing, are linked to her hepatitis C.

ANONYMOUS

21. The course of her illness is that she started developing migraines in 1987 or 1988 and she later found out that she had hepatitis C when we were both tested for HIV, which we didn't have, because I had been ill for a long time. Then she was treated for hepatitis C and that is when her health really started to deteriorate.
22. My wife was treated with Interferon and Ribavirin. She lost hair on top of the top and back of her head and her follicles got infected. Her head was covered in scabs. Her eyes were sunken and black. She had sores all over her body, including on her chest, arms and back. She was very ill to the point where the nurse wanted her to stop the treatment. My wife called the treatment "drugs from hell". We used to laugh because every clinician pronounced the name of the treatment differently. She felt tired all the time. She went to work and only ever told her manager about the hepatitis C. Her manager was very good to her. She worked all through her treatment except for the last two weeks of her treatment, when she was very ill. She was very brave. She had to hide everything from her colleagues and it was very hard. Her photograph for her work pass was taken when she was very ill and she looks horrible in it. **W** is not a stupid woman, she has a degree and works for **GRO-B**. **GRO-B**. She wanted to make further progress in her career, but because of the hepatitis C she lost all ambition to move further in her career.
23. There were no obstacles in having access to treatment, but the way that she was spoken to by Dr Bhattacharyya was horrible. Most healthcare professionals have been good. Even then, they have never mentioned contaminated blood. When we discovered the Skipton Fund, my wife told Karen, the clinical nurse and she said: "I should have really told you about that, but I forgot". I don't know if the nurse forgot or if she was reluctant to tell us, but she did help quite a lot later on providing documents for Skipton.
24. I don't think any other treatments should have been offered that were not. There were older treatments, but the new treatment was offered that was a four-month course rather than one year. The old treatment was just as hellish.
25. My wife was constantly depressed throughout the treatment. I cooked, cleaned and did everything for her. She was incapable of doing anything because the treatment sucks the life out of you. She still suffers from depression and doesn't understand why. Her mental

ANONYMOUS

health was severely affected by the treatment, she is still not the same person. She has moments where she forgets what she is doing and she leaves the oven or the cooker on. She has become very forgetful. This started with the treatment and has never gone away. There was no follow-up and no support offered after the treatment. She was just sent home after it. I don't even know if this inquiry is going to bring closure. We don't even know what is going to happen and we are very angry and talk about it all the time. We hate that people knowingly did this to us and it is perfectly human to want to find out the truth and the reasons why this happened. Thank God for the Scottish Government or we would not understand half of what went on. It was the report that was an attempted cover-up but thanks to the Scottish Government this has been recognised. Hopefully, we will get results. Compared to some people, we are lucky. If we never found out about the hepatitis C, my wife could be dead.

26. Since she found out that she had hepatitis C, my wife would not go to the dentist or be in a situation where a blood transfusion might be needed. She has a plate and it broke a few months, but she would not go to the dentist to fix it. **GRO-B**
GRO-B She will not go to hospital unless she is very ill or on a stretcher. **GRO-B**
GRO-B This is a constant source of worry.
27. Her hepatitis C diagnosis has affected our private, family and social life. We don't have a social life anymore. During the period between 2010 and 2015, knowing that she had hepatitis C, she couldn't tell anyone. Only our sons and daughters knew. Our son got tested and he was clear. It was not discussed. There was paranoia about infected children and friends. No friends were told for fear of the stigma. Only close family and **W** manager know. We go on holiday and the hepatitis C has not been a problem. We are off to Fuerteventura on Saturday and we are not getting travel insurance because **W** would have to explain her hepatitis C and there is a stigma about it, and companies sell your personal details and pass them on to others very easily, and we are scared of what the outcome could be.
28. As concerns the stigma, I have already explained the way Dr Bhattacharyya addressed my wife and how he offended her. We discussed hepatitis C with family, but I suspect that if I was one of them I would be wary of situations where there are wounds. My wife also

ANONYMOUS

has the additional problem that she is allergic to plasters and has to use white tape to contain or cover wounds so she wouldn't leave the house with a wound.

29. My wife has the intelligence and experience to do well at work but has lost ambition, maybe because of the stigma and because of her depression. Depression kills you ambition. [GRO-B]
[GRO-B]
[GRO-B] has to work to pay for things now as I cannot work. She has never stopped working, except for the last two weeks of her treatment. It was so difficult as she was so ill and she is still in a lot of pain. She shouldn't be working. [GRO-B]
[GRO-B]
[GRO-B]. I do the cooking and the cleaning, but I cannot work anymore. [W] has to work so that we can afford to live.

Section 6. Treatment/Care/Support

30. There was never any care, support or counselling offered as a result of my wife becoming infected with hepatitis C. Karen the nurse gave us her professional NHS telephone number so that we could contact her if we ever had any problem. This was in case severe complications arose from the treatment. No help or advice was offered either before or after treatment or at the time of the diagnosis.

Section 7. Financial Assistance

31. [W] got a Skipton Award and there is a new thing coming out. We understand that stage 1 is chronic hepatitis and that stage 2 is liver damage and there has been a recommendation that stage 2 patients receive a yearly award, but I believe that both should get the same award. [W] has applied for it, but will not know how much it is until December. We get more information about these things now than we did in the past. We received a few letters from the SIBSS. [GRO-B]
[GRO-B] but we struggle to navigate their site as it is really bad. I do not necessarily

ANONYMOUS

think that the site is bad in order to put people off. It is slightly intimidating, especially the Skipton Fund.

32. We found out that financial assistance was available through our own research of the SIBF and Haemophilia Forums. We discovered the Skipton Fund and it took a whole year before we found out that we should have been informed about it properly. This was already after the treatment. My opinion is that the cover-up is still ongoing. How can you ever have confidence in inquiries when so many have been a whitewash?
33. **W** received an initial £20,000 payment and a further £30,000 payment. This was in Spring 2016. She gets a wage top-up of £50/month. She shouldn't be working, but she has to because of my **GRO-B**. Money doesn't compensate for all that they have put us through. I'd rather have my healthy wife back. When **W** got these payments, she couldn't touch the money. She felt like she lost a baby and was being rewarded for it. Accepting the money, to her, was like accepting the sacrifice of our child. That is how she feels. How can you be pleased that you receive money after what happened? I see money awards as a justification or acknowledgement of what they did to us. They are trying to cover it up. They are sneaky and have never admitted it properly. The politicians apologising for all this were never in power when it happened.
34. The process of applying for financial assistance was filling in forms and sending them.
35. When you send the forms, they bounce back to you a couple of weeks later and you are asked to prove things and to find evidence which is non-existent. You have to re-apply again and then are rejected again. She had to appeal and that is where the Skipton Panel came in. Evidence was given to them by my wife's friend and by myself as I have explained earlier and they produced a verdict that the blood transfusion was most likely how my wife became infected.
36. It is understandable that you are asked to prove things but I do wonder how many people don't even know that they are entitled to financial assistance, and how many people have liver disease that has not been caused by alcohol.

ANONYMOUS

37. I think that there was a concerted attempt to stop [w] from getting information. We went to many channels to get medical records and were told that they must have been destroyed. I do not know whether they didn't know what had happened to the medical records or whether they simply couldn't be bothered. It was a difficult time. We wrote to many people to obtain evidence. We felt like we were being restricted. It was not easy at all to obtain information.

I have never received any payment myself. I think that would only happen if my wife died.

Section 8. Other Issues

38. We have never been involved in court proceedings, campaigning or in the Penrose Inquiry as a result of [w] becoming infected. We were not even aware that the Penrose Inquiry was taking place.
39. We couldn't find any documents as my wife's medical records are missing. A child's medical records cannot be destroyed, I think. Our baby lived for 15 hours and must have had a medical record, but I believe that too must have been destroyed. There is no information about my wife or about the baby that died. A member of staff from the Scottish Blood Unit tried to help, but couldn't find anything.

ANONYMOUS

Statement of Truth

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

Signed

GRO-B

Dated 13/12/18