

Witness Name: GRO-B

Statement No: WITN2143001

Exhibits: None

Dated: 12th November 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 5th November 2018.

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

Section 1. Introduction

1. My name is GRO-B. My family normally call me GRO-B. My date of birth is GRO-B GRO-B 1941 and my address is GRO-B I am GRO-B: W 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 and I have been married for GRO-B.

Section 2. How Affected

3. My wife had a hysterectomy operation in 1989. During the operation, she received a blood transfusion due to the loss of blood she had experienced. She unable to do very much because of the operation. The hepatitis C symptoms did not start immediately. On 24th April 2002 she saw various doctors about the hepatitis C symptoms.
4. The nature of her hepatitis C was moderate to severe and had a great impact on me as I had to pick up all the pieces from what happened to my wife.
5. The blood my wife received was normal blood which she received at the time of her transfusion. She received three units of blood but I have no idea where the blood came from. She did not receive blood products, only blood from a transfusion.
6. She received the blood transfusion at Dr George Anthony was the person who performed the surgery and ordered the blood transfusion.
7. She received the blood transfusion on the night of the seventh to the 8th December 1989.
8. No advice was given beforehand about the risk of being exposed to infection through the blood transfusion. It was a long time until the first hepatitis C symptoms appeared. My wife did not recover particularly well after the operation but the hepatitis C infection itself lay dormant for a long time. My wife had a slow recovery from her hysterectomy operation.
9. As far as we know, was only infected with Hepatitis C and not with any other viruses.
10. Prior to her hepatitis C diagnosis, my wife had been attending her GP very frequently, on many occasions to do with an underactive thyroid. It was then that she received the diagnosis. By that time, the symptoms had increased, she had constant fatigue and an itch all over her body which was unbearable. She was told that she needed a liver function test and a thyroid test. This happened in May 2005. She was then sent to

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Hospital for a test and a liver scan. At GRO-B Hospital, she saw Professor Jang Dilawari.

11. It was Professor Dilawari who later told me that W had tested positive to hepatitis C. This was in June 2005. He asked if she had ever had a blood transfusion and she told him about the blood transfusion that she had back in 1989, at the time of her hysterectomy operation. On 30th August 2006, W had a liver biopsy. She was found to have autoimmune hepatitis which can be attributed to interferon and ribavirin.
12. I was told that my wife would need a great deal of support with tasks such as getting showered, getting dressed, doing household tasks and many others. I personally did not receive any information about how to manage the infection. We had to find out a lot of information to understand and manage the infection on our own. We were able to do this by going to Roche Pharmaceuticals. We attended the Sign Guidelines meetings in Edinburgh. We attended the Sign Guidelines at our expense. We had to cover even hotel expenses to attend in order to be able to find out a bit more information from doctors, consultants and other health professionals. We already knew that it would not be advisable for her to drink alcohol or eat fatty foods. This did not make a difference as W has never been a drinker. We knew because of how the hepatitis C was affecting my wife's liver. At Prof Dilawari's suggestion, I went to my GP and got tested for hepatitis C. I was found not to be infected.
13. We were only given dribs and drabs of information to begin with.
14. I would not be critical of the doctors. I think they were helpful and we all learned as we went along.
15. Even though I was found not to be infected, I am aware that there would have been a risk to me as a result of my wife being infected. I had to find out how not to become infected at the Sign Guidelines. We were told to be careful with toothbrushes and toothpaste, and the healthcare professionals who attended were good enough to explain again everything that we thought about the risks of contracting the infection.

Section 3. Other Infections

16. My wife contracted hepatitis C as a result of being given infected blood products.

Section 4. Consent

17. I do not think that my wife was treated or tested without her knowledge or without her consent or without being given adequate or full information nor for the purposes of research. I believe that all medical studies are a learning process.

Section 5. Impact

18. My wife suffered considerable mental and physical effects as a result of being infected with hepatitis C.
19. Physically, she was in constant pain and psychologically, she experienced periods of depression.
20. She developed a heart condition as a result of her hepatitis C. This condition is called atrialfibrillation and it means that her heart races fast and has to be controlled with medication. The infection also caused her to develop an underactive thyroid, which has to be controlled with medication. Her auto-immune hepatitis is now controlled. We received a letter informing us that it was the Interferon and the other medication that caused her hepatitis C to develop into auto-immune hepatitis. It was the hepatitis C that caused this condition. [W] currently takes Azathioprine (quite a heavy dose of 150 mg per day) and Levothyroxine (75 mg a day). She also takes her heart medication, Atenolol (50 mg per day).
21. The course of her illness was gradual. The first hepatitis C symptoms started in 2002 and she attended her GP. It took a long time for the GP to see that there was something not right. Now my wife has blood tests every 3 months and sees the auto-immune hepatitis doctor every year. His name is Dr Priest. Prior to that, she saw Professor Dilawari and then Professor Mills. The illness continues.

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22. The treatments that she received lasted for a period of six months and they were successful in suppressing the hepatitis C. She was receiving tablets daily and Interferon injections weekly. She was able to inject herself. She has never been for a private blood test. She receives blood tests all the time for her auto-immune hepatitis at GRO-B Centre.
23. We had no difficulties or obstacles in accessing the treatments because my wife was quite forceful, even though she was quite old at the time and not sure of what the outcome of such treatments would be.
24. I don't think there were any treatments that ought to have been offered and were not made available to us.
25. The medication took a toll on W. She lost a lot of weight and developed a heart problem. There were many things that she was unable to do and this had a big effect on our family life. At one point she was in bed for at least 6 months, as she was on two different treatments every week. The implications of auto-immune hepatitis are very much the same as the implications of hepatitis C. She is fatigued all the time, not able to do any of the activities that you would normally do, she still experiences itches all over, she has experienced a weight gain and is unable to do any sports. She tries to walk because the terrain here is flat, which makes it easier.
26. When my wife told her dental hygienist about the hepatitis C, the hygienist asked: "*should I be treating you?*", but she eventually did. My wife has always been upfront with any dental practitioners. She always informs her hygienist and her dentist of any issues, including her hepatitis C. At the local Hospice, my wife was able to get a massage to try and relieve aches and pains. This helped, but the relief was only temporary and ended was soon as the massage was over.
27. The impact that being infected with hepatitis C had on our private, family and social life was considerable. We don't go out as much as we did before she became infected. Our family found it very difficult to accept and to this day they don't want to talk about it. They

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were very shocked. This did not cause any strain with our children but we are not able to spend as much time with the part of our family that live in America. We have not been able to visit in three or four years and we don't see them as much. This is a big problem because hepatitis C has an effect on American Authorities and presents an added problem when trying to obtain travel insurance. We managed to go abroad a year ago in January.

28. I would say that there is a stigma associated with a diagnosis of hepatitis C because it means that sometimes barriers go up with people. When they know what the illness is that my wife has had, you can see change in their attitude. It is not a tremendous change, but it is there. I think this is to do with fear of the unknown, as they do not know much about the illness.
29. My wife used to work at the [GRO-B] and had to retire at the earliest possible age that she could. She was 60 years old when she retired. Had it not been for the hepatitis C, she would have retired at age 65. However, she had to retire earlier because of the hepatitis C symptoms that she was experiencing. Even though she had not been diagnosed by the time she retired, she was already very sick. The financial effects were noticeable. There was a big difference in income and I would say that we were not as affluent as we might otherwise have been.

Section 6. Treatment/Care/Support

30. No care, support or counselling was ever offered to us as a result of my wife becoming infected with hepatitis C.

Section 7. Financial Assistance

31. We did receive financial assistance as a result of my wife contracting hepatitis C.
32. When she was first diagnosed with the disease, Professor Dilawari filled out a form. Within days, we received our first award.

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33. We received an initial lump sum payment of £20,000. Since then, we received nothing until two years ago, when the Scottish Government paid £30,000 to us. The first payment came from the Skipton Fund and the second payment came from the Scottish Government. The Skipton Fund has also paid £500 towards heating on two or three separate occasions, but they **would not** backdate the payments that we had already missed. We don't currently receive any monthly payments, but there has recently been a review and it seems like the Scottish Government is going to pay some amount and that this will be backdated to 1st September 2018. However, I don't know how much the Scottish Government will pay.
34. The process for applying for financial assistance was simply filling in forms and posting them out. There was no need to produce evidence of payments that we had already received.
35. I have two criticisms to make regarding difficulties or obstacles in obtaining financial assistance. These are regarding heating allowance. My first criticism is that payments cannot be backdated to receive the payments that you have missed. My second criticism is that if my wife had not found out about heating allowance and initiated the process to claim it, then they would not have sent any payment despite my being entitled to it.
36. I cannot think of any preconditions imposed on the grant of financial assistance, but I think that some grants were means-tested.
37. My main observation, other than the fact that some payments are not backdated, is that the payments that we receive are derisory and not enough to compensate for everything that we have been put through.
38. I have never personally received any payments from any of the Trusts or Funds due to my wife becoming infected with hepatitis C.

Section 8. Other Issues

39. We have never been involved in litigation concerning the use of infected blood and we have never been involved in campaigning either. My wife was involved in the Penrose Inquiry, but I was not.
40. As concerns any documents which might be relevant for the purposes of the Inquiry, I would bring to your attention the letter signed by Dr George Anthony saying that my wife received three units of blood on the night of 7th to 8th December 1989. We keep a copy of this letter. I have also had sight of another letter saying that Interferon probably triggered my wife's auto-immune hepatitis. This is a professional opinion expressed by Dr Jang Dilawari.

Statement of Truth

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

GRO-B

Signed

Dated

30 March 2019