

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN2861001

Exhibits: 0

Dated: 20 November 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B My address is known to the Inquiry.

Section 2. How Infected

2. I believe that I received infected blood on GRO-B 1970 when I had my second daughter at St John's Hospital maternity unit in GRO-B This hospital no longer exists. It was rather a traumatic birth, eventually I had a caesarean section. I lost a lot of blood, I think I had to have 4 or 6 pints of blood via a transfusion. I was totally out of it, I was not aware that I was being given this blood. It was only when I came around that I was told that I had been given a blood transfusion. I stayed in hospital for about 10 days after that. At no point was I told of any risk of infection via contaminated blood.

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3. Many years later, in 1991, had a pain in my knee and went to my GP who told me he thought I had arthritis. At around the same time we decided to buy our house, we lived in the property already as sitting tenants. Because of my arthritic knee the mortgage providers were not happy for me to have my name on the mortgage without having a blood test first. In around March 1994 I asked my GP for a blood test, the results showed that I had something wrong with my liver. I had noticed over the previous months that my eyes were sometimes yellow and sometimes had burning in my chest and acid at the back of my throat
4. My GP referred me to GRO-B Hospital. I was not told what might be wrong, just that I had to go and have tests. I can remember that the doctors were all gowned and gloved up, it was quite horrendous, quite frightening. I vaguely remember someone saying that they were testing me for HIV, and I nearly had a heart attack. When the tests came back they said that I did not have HIV or hepatitis C, but that I had primary biliary cirrhosis. I was told that it was at a very early stage and that for the time being I did not need any treatment. I asked for yearly check-up appointments so that my condition could be monitored. Since then I have had constant treatment from the hospital.
5. I believe that there is a link between the blood transfusion that I had in 1970 and the primary biliary cirrhosis. I have often thought about what could have caused these liver problems. I did not make the connection straight away. I did not know anything about contaminated blood until I started reading bits and bobs in the paper. In the last few years there has been an awful lot in the press about people receiving contaminated blood in the 1970s and 1980s. I suddenly thought that this could be why I had cirrhosis. I had such a big transfusion in 1970, I started thinking maybe this could have been the cause of it all.
6. When I was diagnosed I did not discuss with my doctors the possible cause of the cirrhosis. However I did ask last time I saw him whether he thought that it could have been caused by the transfusion I had. He said it could be but it

could also be hereditary because my mother died of liver cancer. Nothing more was said. I think he did not wish to say too much, but I question whether I have been told the whole truth.

7. I do not believe that I was given adequate information about my condition when I was diagnosed. I believe that I have been left in the dark, they test you and then have a little chat with you and then that's it, you are out the door.
8. Cirrhosis of the liver or primary biliary cirrhosis was never explained to me. All I knew was that I had problems with my liver, and that can be quite daunting to hear. I have found a letter in my records dated June 1995 which states that I was reluctant to take medication. I have no recollection of being offered treatment at that time, it would be very unlike me to refuse to take medication, especially as I was so worried about the diagnosis and what it all meant. I was eventually prescribed Ursodeoxycholic Acid tablets in June 2000, I just took these tablets like they told me and hoped that everything would be alright.

Section 3. Other Infections

9. When I was diagnosed I was tested for HIV, Hepatitis A, B & C and I was told that all these tests came back negative. I do not know which infection or infections I contracted as a result of receiving infected blood. However I strongly believe that my cirrhosis is linked to the transfusion I had in 1970.

Section 4. Consent

10. As far as I know I have not been treated or tested without my knowledge, without my consent, without being given adequate or full information or for the purposes of research.

Section 5. Impact

11. Since having my third child in 1972 I have never been without some form of tiredness. The tiredness has just increased since then. I have always had to have my nanny nap, as we call it, in the afternoon. Before I was diagnosed in 1994 I suffered from gross tiredness, I did not go to the doctor because I thought it was just running about after the children that was making me feel so exhausted.
12. In the last few years the fatigue has become really bad. I started taking B12 injections about a year ago, it works for probably about six weeks. I still have to have the nanny nap mind you. The B12 does make me feel a lot livelier, but after it wears off I am practically begging for them to give me another one.
13. I have an appointment at GRO-B Hospital every six months for a liver scan. I always have a blood test and am weighed beforehand. The doctor that I have now is the only one who has ever really explained anything to me; he tells me what's what. He told me that the cirrhosis can turn into cancer. He explains all of the procedures and has tried to make things easier for me. He has said that there is not any long term treatment available for me. Other than him I have never really had any joy with any other doctors.
14. In March 2013 I had a routine appointment at GRO-B Hospital and was told by my doctor that he did not need to see me anymore. I was discharged from the clinic. A few months later in July 2013 I went on holiday with a friend to Eastbourne. We were out shopping and suddenly I started to waver. I said that I felt really sick and she dragged me inside the nearest doorway which happened to be a cinema. I just started throwing up blood, loads and loads and loads of blood. The staff at the cinema brought out a black bin bag for me to vomit into. It was terrifying. Eventually an ambulance arrived and I was taken to Eastbourne Hospital where I stayed for three days. They said that I had oesophageal varices which had burst. It was such an awful experience; I am in

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constant fear even now of having another bleed. I still occasionally feel nauseous but nothing like that has happened since.

15. I have suffered both mentally and physically as a result of having cirrhosis of the liver. I am quite a tough cookie really. I try to avoid doctors as best as I can but I do seem to spend more and more time at the hospital and at the GP surgery. I do worry a lot. I go to bed some nights and wonder whether I going to wake up in the morning. I just feel as if my life has been put on hold. I am a very very active person, I love to do things, I love to be in amongst people and be active but I have lost it all. I feel as if I am being tormented because I can't do the things I want to do.

16.

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But I loved that job and did it for 21 and a half years. I would have stayed for many more years but eventually I got to a stage where I just felt that I had to give it up. I was worried that if something happened, if someone had a fit or a fight, I would not have the strength to deal with it. I was getting to the point where I was almost too tired to get up out of the seat. If I did not have this wretched tiredness I believe I could have worked until I was over 80.

17. I retired from that job in December 2015. After that I found my days were so long and boring, and felt that I had to do something. By chance I started talking to the head teacher at the local catholic school where my children had been taught, she suggested that I do some voluntary work at the school. I jumped at the chance. I started working at the school in July 2017, I would work a few

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hours a week assisting the teachers and showing the children how to write their letters. But in early 2019 I had to give this job up too, I was just too tired.

18. I have never taken one solitary drink since 1994, at weddings and other occasions that is really quite hard. Before that I never drunk a lot but I used to like a glass of wine or a glass of champagne at a wedding. I know it is not the be all and end all but it does have an effect.
19. The tablet scenario is quite a lot to deal with; I have to take five tablets in the morning and three before I go to bed. I do not feel the side effects of the tablets but it is onerous to take them. Once we went on holiday to Norfolk and when we got there we realised that the tablets were still sitting at home so we had to come all the way back to get them. Its silly things like that. If I go out in the evening I have to take the tablets with me and to make sure that I am close to water. It's a pain.
20. I do feel that it has definitely slowed me down especially as I have got older. More so than my friends who are the same age as me and who are full of life and raring to go. In the past I had been the real lively one but this cirrhosis has knocked me for six.
21. People will say "you are 74 now, you should be slowing down!" but that's not my mentality, I want to do things but I can't do them. I would love to continue to do my teaching, and there are so many things that I would like to do and see. I rarely go out because I am always so tired. It used to be nothing for me to go out 5 nights per week and get up early the next day. My husband's family live in Ireland, he does not like flying and so to get to them we have to get a boat and then a train. I am just not fit for doing that any more.
22. I used to cook on a Sunday for my brothers, my children and my grandchildren. It was nothing for me to cook for 12 people. Now it is a real effort for me to cook Sunday dinner for three. I am sad that I am not as lively as I used to be, it

all seems to be catching up with me. The good news is that I am not in any pain, that's the most important thing

23. The problems with my health have definitely had an impact on those close to me. My two daughters and my son watch me like a hawk; they ring me up three or four times per week to make sure I am ok. My daughter **GRO-B** who was born in 1970 believes that it is her fault that I am ill because I had the blood transfusion after she was born. My son was so worried about me when I was in hospital in **GRO-B**. It has also had an impact on my grandchildren. When they go away I get texts from them and they bring me nice gifts, only because they worry about me.

Section 6. Treatment/Care/Support

24. I have not faced any difficulties or obstacles obtaining treatment care and support.
25. I have never been offered any counselling.

Section 7. Financial Assistance

26. I have read a lot about the Skipton Fund. I have not attempted to apply.

Section 8. Other Issues

27. My interest in the Inquiry has nothing to do with money. It is to do with getting answers and getting satisfaction. I would not be involved or go through all of this by giving a statement if I did not think that it was possible that I had been infected. I have been told that my liver problems could be hereditary, but there were six of us kids and none of the others have had any problems with their

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liver. I am the only one who has had a blood transfusion. I would really love to know whether the blood that I was given in 1970 was infected.

28. If it turns out that I was not given contaminated blood or even if I never find out, I still want to see justice done. All the people that have suffered as a result of these blood transfusions are probably getting a bit long in the tooth now. It is important that they have the satisfaction before they leave this earth of knowing the truth and that they have enough money to enjoy their final days. That for me is what it's all about.

Statement of Truth

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

Signed

GRO-B

Dated

...20/11/2019...