



Witness Name: **GRO-B**

Statement No.: WITN2243001

Exhibits: NIL

Dated: 24/06/2019

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 5th November 2018.

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

Section 1. Introduction

1. My name is **GRO-B** and my date of birth is **GRO-B** 1977. My address is known to the Inquiry. I am **GRO-B: H**'s wife. I intend to speak about my husband's experience of being infected with hepatitis C upon receiving infected blood products. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on me and our lives together.
2. **H** and I got married 5 years ago, but we have been together for 17 years.

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Section 2. How Affected

3. [H] was born in 1974 with severe haemophilia. He was treated by receiving Factor 8 (blood products) at Yorkhill hospital, Glasgow and then administering injections himself. That is how he contracted hepatitis C.
4. [H] s haemophilia is severe. It is only now that he can lead a normal life. At the time, haemophilia was very disruptive. He went through bullying at school because of his Hepatitis C. There was a lot of ignorance about the illness. [H] could not go on school trips or take part in any physical activity. He only had a small group of friends. Any little bump would lead to blood loss. A small push could result in serious bleed. [H] missed out on a lot of things that are part of growing up, such as skating, footballs or riding a bicycle. Even pressure from nappy pins from old-fashioned nappies, used when [H] was a baby, could cause major bleed inside
5. [H] received Factor 8 to treat his haemophilia. Blood replacement products in the past were made up from a collection of different bloods. These came from American prisons, where many prisoners were drug users and were getting compensation in exchange for donating blood. [H] told me this information. Haemophiliacs got infected over and over again when they received these blood products. [H] must have received blood products about three times a week on average to control his haemophilia. [H] was infected over and over again. [H] told me this. He could have been infected with HIV, but he was lucky. There is proof that they knew they were infecting him. I will discuss this later. The blood replacement product that [H] receives is still called Factor 8, but the product was developed and it does not need to be refrigerated anymore. We can keep it at home and [H] can administer the product himself.
6. When [H] was a child, he was treated at Yorkhill Hospital in Glasgow. When he became 16 years old, he was transferred to the Royal Infirmary in Glasgow, in particular he was treated at their Haemophilia and Thrombosis Unit. He is still treated there. I cannot give any details regarding doctors that treated him as I might not remember correctly, but all this will be documented in [H] s medical records.

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7. It is hard to pin-point the exact date when [H] was infected with hepatitis C, but this definitely happened when he was a child. He was 19 years old when he found out officially. [H]s employers knew that he was infected before [H] found out. [H] is a civil servant and works for [GRO-B] the UK Government. I do not know how they knew he had Hepatitis C before [H] I assume they got this information from [H]s GP.
8. [H] became infected with hepatitis C purely due to the blood products that he received to treat his haemophilia. I confirm that I know of no other way he could be infected.
9. There was never any information given to [H] about the risk of contracting an infection from the blood replacement products that were being used to treat his haemophilia. Administering these products was the only way to help him when he had a bleed. At the time, haemophiliacs did not live past their twenties. The information provided about the treatment was very minimal. The blood replacement products were the only treatment available and that was the only way to deal with haemophilia. There were no other options given to [H]
10. [H] never received any other infection apart from hepatitis C. He has received three letters from the NHS from Professor Lowe, Doctor Walker and a Professor Tait. All three letters have these professionals details on. The first letter was dated the 26/11/2002 indicating there is a small risk that he might have been infected with mad cow disease. The second letter was also from the NHS from the same professionals. The last letter he received was in February 2009 stating the same as the previous two letters that there was a small risk that [H] might be infected with mad cow disease. However, no one can be tested to determine whether they have contracted mad cow disease. It is only ever possible to find out if a person had mad cow disease once that person is dead. The letter indicate that [H] might have been infected with mad cow disease at some point in the past, but they do not specify when exactly this might have happened. Symptoms for mad cow disease are very similar to symptoms for hepatitis C until the very late stages, so this is an added worry now.
11. [H] found out about the fact that he had been infected with hepatitis C when he was 19 years old. He was called in the haemophilia clinic at the Royal Infirmary, Glasgow and

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went into the consultation room alone. Then he was told about the hepatitis C and given a leaflet. He went back home thinking that was his death sentence. He thought that he would be dead within a few years. Then he discovered that his employers already knew about the infection. This happened when he contacted the Human Resources department at his workplace to let them know, and they confirmed that they already knew that [H] had hepatitis C. [H] is a civil servant working for [GRO-B] [GRO-B] the UK Government.

12. [H] s doctors provided very little information about the infection and [H] and his parents had to find out a lot through their own research.
13. The doctors offered to perform a liver scan on [H] because he is not a suitable candidate for a biopsy due to the risk of bleeding. [H] can only be assessed through liver scans and blood tests. Liver scans can tell you whether your liver is enlarged or presents any growth or tumours, and blood tests can tell you whether the normal values present any alterations. [H] was diagnosed with fibrosis of the liver. I believe [H] s first liver scan was in 1994 and he had one every year until about five years ago. This was at the Royal Infirmary, Glasgow.
14. [H] was offered anti-viral drugs, but he took a horrible reaction to them and had to stop taking them some time ago. Medication to try and stop the virus was offered to [H] when he was twenty years old, shortly after he was told that he had hepatitis C. The doctors told him that there was a chance that he might react to this medication, as there were side-effects. He was told about this, but they were hoping that the side-effects would not be as bad. However, [H] experienced horrible sickness and rashes and was only able to take the medication for two weeks.

Six years ago, [H] was lucky enough to qualify for a new treatment which resembles chemotherapy and has the same side-effects. It was very hard. The virus is now present, but is either not active or presents minimal growth. Even though the side effects are horrible, you only ever get one chance to try this treatment, so we decided to take it. Other than these treatments, [H] received no advice from his doctors about how to understand and manage the illness. In between treatments, [H] managed his illness by making healthy life choices, such as avoiding alcohol and fatty foods. He

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experienced fatigue, illness and extreme tiredness. He still experiences these symptoms at times, but at least they have not become any worse. However, the damage that was done before the treatment still remains. As [H] is unable to have a biopsy, we do not know whether he could still experience a sudden and quick illness leading to death. No information was ever provided by [H] s doctors regarding healthy lifestyle choices, meaning that [H] and his parents had to find out about these matters online and from older members of the Blood Inquiry group. The only things provided by the hospital were blood tests, liver scans and treatments, but no advice whatsoever. The doctors did not even tell [H] that he was highly contagious.

15. My opinion is that information should have been provided to [H] earlier, preferably on the same day when he was told that he was infected with hepatitis C. He should then have been given access to a liver specialist and to a psychologist, and he should have been provided with a lot of information on hepatitis C. They also should have told him that he was infected straightaway, as soon as they knew, rather than when they did.
16. My view is that given the fact that [H] was a teenager or young man when he was told that he was infected, the doctors should have thought about the fact that [H] was having girlfriends and/or sex and that he could have infected these women. They would have never known and it would not have been [H] s fault. [H] never had lots of girlfriends, but the point is that he could have, and so he could have infected other people. I had to actively find out how to avoid being infected and make sure that I knew everything. For these purposes, I went to Sandyford Sexual Health Clinic in Glasgow and booked an appointment there. This was some time in the middle of 2002. They were very good and I was offered support and information. I complemented this with the information that I found online. At that point, [H] and I decided not to have any children.
17. [H] was never told anything about the risk of others becoming infected as a result of his infection. It was only later on, when he asked more questions and had an appointment with the liver doctor that he was able to find out a bit more. At this point, it was months since he first found out about the infection. It was [H] s mum and dad who worried about hepatitis C being contagious and pushed [H] to find out more, it was never the doctor's initiative. [H] s mum is called [GRO-B] I am aware that you have her personal details. [H] s father's name was [GRO-B] who is now deceased. Hepatitis

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C was associated with drug users at the time because of the needles that these people might share.

Section 3. Other Infections

18. [H] never received any infection or infections other than hepatitis C. He was never infected with HIV or HBV. It was only recently that he has started receiving letters indicating that there is a risk that he might have, in the past, been infected with mad cow disease. This has been a further source of worry for us as it is not possible to be tested for mad cow disease and infection is only discovered after death.

Section 4. Consent

19. I confirm that I believe that [H] was treated or tested:
- a. without his knowledge, and
 - b. without his consent, and
 - c. without being given adequate or full information, and
 - d. for the purposes of research.
20. There are notes in [H]'s medical records confirming that the doctors knew that the blood they were administering to treat haemophilia was infected with hepatitis "non A - non B" and yet they continued using these blood products. One of the doctors confirmed in writing that they wanted to do some kind of experiment and see how people's health would deteriorate when infected with hepatitis C, so they used haemophiliacs as guinea pigs to study how their body changed because of this new disease. This doctor belonged to the team that worked at Yorkhill Hospital. I do not know the name of the Doctor. All this is in writing, you will find it in [H]'s medical records. This was all passed on to the Penrose Infected Blood Inquiry. Some records were removed and then lost. We know about this because [H]'s employers requested [H]'s medical records on the same year when [H] found out that he was infected with hepatitis C. I do not know the exact

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date but [H] would have been around 19 years of age at the time. This caused me great shock because this is a matter that people are not normally aware of until they have a family member who is affected by these circumstances. It is awful. Many children and men have died after being infected, it has affected their wives. All this could have been avoided. Factor 8 was the only treatment available, but the blood imported from America could have been tested and discarded, and different blood obtained. There would have been another blood replacement product of the same kind, but safe and obtained from healthy donors.

Section 5. Impact

21. This situation has had a great impact on us.
22. Mentally, it has been very stressful since the time when [H] found out about the illness, as hepatitis C can be quick and fatal. When [H] first found out, he expected to live for another three or four years. His friends were planning weddings, buying houses and having families, and he thought that would never happen for him. He was very aware of the stigma associated with the disease when meeting new friends. Even as a child, before he even found out about the hepatitis C, something in the news caused him to be moved to a corner in the classroom without the teachers even bothering to ask [H] s parents about his condition. Now [H] has a job, he has me and he has a good family, but he is constantly aware that the illness might come back and start again. This is always on the back of his mind. Once we decided not to have children, we were okay, but there are always worries. I see the stress that he has been experiencing because he has been campaigning for twenty years and many of his haemophiliac friends have died. This has affected him very much. His friends have died because of hepatitis C and some because of HIV.
23. Physically, [H] is very tired and his concentration is bad. He works in the office, and he works full-time, but he can only do minimal paperwork because of his issues with concentration do not allow him to do more important work.
24. [H] s liver function is abnormal. He is now 44 years of age. Because of his lifestyle, he has been able to stop additional health problems from developing further, perhaps into

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something worse. His main problems are that he experiences fatigue and lack of concentration. He attends two check-ups a year. His immune system is very low. The flu, a cold or any other virus will affect [H] twice as much as it would affect a person who had not been infected with hepatitis C.

25. [H] completed his second course of treatment six years ago and it was successful, but it did cause him to develop asthma and eczema. We were told that side effects could be quite serious. Some patients become suicidal, depressed, with no appetite, experience weight loss and hair loss, or become violent. Twice, [H] wanted to stop the treatment because he was so sick and had no energy. He went from the couch to bed and from bed to the couch all the time. He was off work for almost a year. However, he did manage to complete the treatment and is happy that he did. The first course of medication, back when he was in his twenties, caused him to sustain bad rashes all over his body and be violently sick, so he was advised to stop the treatment. The side-effects of this first course of medication did not last very long and he was cleared within a few days.
26. The first treatment that [H] was offered was meant to help with his hepatitis C. In order to qualify for the second treatment, he had to be tested as success depended on his genotype. He qualified for the treatment and decided to take it. Things were not made hard for him in this respect. He had regular check-ups throughout the duration of his treatment.
27. Although [H] faced no obstacles when it came to access to his treatments, the doctors now consider him to be cured. This means that he is no longer being offered liver scans. We would like at least one liver scan a year. This scan would identify any changes. We have been told that changes can still happen and the treatment that [H] had is quite new, so it is hard to know whether the hepatitis can become active again. [H] would now have to cover the cost of a liver scan privately. I am trying to convince him that it would be a good idea for him to do so.
28. In my opinion, [H] should have been offered psychological support when he was younger as well as the support of a nutritionist as extra help. These were never offered and I don't know why.

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29. The mental and physical effects of the treatments [H] received are as discussed. [H] experienced rashes and be violently sickness with his first treatment. The effects of his second treatment were akin to chemotherapy, to the point where he wanted to abandon the treatment on two separate occasions. It also caused him to be extremely unenergetic and be off work for almost a year during the second treatment.
30. No dentist will take [H] because he was infected with hepatitis C, so he attends the dental unit at hospital. The haemophilia unit is close, so they can assist if excess bleeding occurs. On one occasion, I tried to book a massage to help [H] relax, and they would not take him. [H] also wanted to apply to work collecting blood, but cannot do so because of his hepatitis C infection. Further, [H] has been in hospital a few times because of spontaneous bleeding from his joints. In particular, from his right ankle. He has been operated on his ankle four times now. The pain is still there. This is a type of arthritis that haemophiliacs develop and gets worse with age. This is a big operation and there is a risk of infection, so [H] has to be treated in isolation all the time.
31. Socially, [H] has not been able to make a lot of friends and participate in normal activities. Family-wise, it has been our choice not to have children. He would feel really guilty to pass hepatitis C on to his children. [H] leads a more sedentary life than he would like. Even things like walking are very restricted. He has lived all his life as if he was an eighty year old. He can go out, but not much. He can move, but not much.
32. I have adapted over the years. At the beginning, it was very new to me. I was worried to become infected, and unsure as to how to behave to make it better. I am very positive and focus on the fact that the hepatitis C virus is dormant. We can still do things together and have a house and two cats. We just have to adapt everything that we do. When I was younger, I expected to one day have children. When we knew that we were going to stay together, one of the conditions was not to have children and I was fine with it. It took me ten years to get sterilised by the doctors as this is something that they are reluctant to do, but I eventually got there. [H] could not have a vasectomy because of the risk of bleeding.
33. There is a stigma associated with a diagnosis of hepatitis C. The majority of people will be scared to interact with someone who has hepatitis C, but if they took the time to ask,

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then they would know that it is okay. However, most people don't take the time to ask. I work in a sandwich shop and [H] told me not to tell my colleagues that he has hepatitis C as there is a stigma attached. I have even heard people say that it is dangerous to use public toilets because you might catch hepatitis C, which is impossible.

34. [H] would have liked to study more or do courses, but because of his concentration problems, it is very hard for him to learn anything new and to remember things. Growing up, [H] wanted to be a policeman like his dad, but he could not due to his haemophilia. Due to the issues associated with his hepatitis C, he is just doing a very basic job and feels like he would have liked to have been more useful to society. When he was off work for six months following his second hepatitis C treatment, he has an agreement with his boss whereby, if he is off work, his salary automatically goes down to half-pay and stays on half-pay for as long as his illness lasts. The six months when he was off work during his second treatment, he received full pay and then went back to work. The agreement that he now has with his boss works better for him as he is off work sick quite often. Due to the hepatitis C, when [H] catches a cold or infection, it lasts for 3 or 4 weeks. If [H] catches a stomach bug, it lasts for 2 weeks. It has not been as bad in the last couple of years, but [H] has still had time off due to bleeding from his joints.
35. I try and work more if [H] is on half-pay. Whenever he has an operation, we have to plan in order to save extra money and that is why we have a small house with a small mortgage that we can manage if we don't have full money coming in.

Section 6. Treatment/Care/Support

36. Care, support, counselling or psychological support have never been offered to [H] as a result of being infected with hepatitis C.
37. I have never been offered counselling or psychological support as a result of [H] being infected with hepatitis C. If I had ever asked, then maybe it would have been offered, but I do not know for certain and they have never been offered.

Section 7. Financial Assistance

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38. By way of financial assistance, we receive a yearly winter payment which is heating allowance. [H] receives disability support due to his haemophilia. They now want to take away the car, but this is something that we will appeal. They have decided that [H] does not qualify to have help for a car. [H] cannot walk to the bus stop and get the bus, the car enables him to move. If we had to privately buy a car, it would be a lot more expensive for us. Hopefully the Inquiry will lead to some sort of help. Years ago, I do not know when [H] received a one-off payment of £20,000 from the Skipton Society fund. He has received payments on a couple of occasions in the past, but he does not receive regular payments.
39. [H] found out about financial assistance when he was still living with his parents and then ten years ago, when he had a horrible bleed in the house, it was recommended to ask one of the charities for assistance towards buying a new matters.
40. [H] has received payments from the Caxton Fund and another I cannot remember the name of on a couple of occasions in the past as well as payments towards buying a new mattress when he bled on our old mattress ten years ago. The Funds are in London. [H] does not receive regular payments. He received £1,000 in the winter, which is heating allowance, but this comes from the Scottish Government.
41. The process for applying for financial assistance is a lot of paperwork and because we both work full-time everyone assumes that we are okay. He could get more money if he didn't work, but working gives him a sense of purpose and, for as long as he can, he will continue to work. The process of applying for financial assistance makes you feel as if you are begging for help. It is a long process. Also, because the virus is in theory cleared, [H] doesn't qualify for a lot of help, and he is very proud. He would not necessarily go and ask for help.
42. I do not think that [H] has applied for financial assistance enough to say that he has faced any difficulties or obstacles in doing so. When we required assistance purchasing a new mattress, it did take a long while to arrive, but it was mostly okay. The payment that we receive for the car comes from benefits, not from the Funds.

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43. There were no preconditions imposed on the making of an application financial assistance and no preconditions imposed for the grant of financial assistance.
44. I think it would be useful if something was given to [H] to try and make things better because of what he was put through. He deserved more information and more accessible information, and no one has even apologised to him yet. Haemophilia Scotland have been very supportive and it helps to be able to relate to other people. People should not have had the added stress of having to look for information themselves. The government should have provided all this information to make things easier.
45. I have never received any financial assistance myself. As a family unit, it would be beneficial because it would take away the worry when I am unable to work because I am looking after [H]. These are times when he cannot work because he is ill and I cannot work because I am looking after him. Due to the hepatitis C, he could not even get a mortgage or life insurance, so I eventually had to get a mortgage in my name. It would be useful if I was also entitled to financial assistance due to my husband's hepatitis C.

Section 8. Other Issues

46. Information given through the campaigners has been amazing. If they had not taken the time at their own expense, then nothing would have happened. There is still a lot of anger after twenty years, a lot of people have died. The campaigners could have just given up. This is a matter that could have been resolved in a few years rather than having to wait for twenty years. Paperwork has gone missing and the government have taken so long in the hope that more people will die and then they will require to pay less compensation. Many single people cannot get mortgages, many others have lost parents or have lost children, and no one has ever apologised. [H] and I have never taken the matter to court, but [H] has campaigned for years.
47. I think that the documents from doctors that stated that patients had been deliberately and repeatedly infected with non A non B hepatitis are relevant to the Inquiry. So as previously mentioned through the statement made by a doctor indicating that he used haemophiliacs to experiment and investigate on hepatitis C, this proves that people being infected was no mistake. Missing medical records are to do with the earlier years when

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they were at Yorkhill Hospital for children. This has not only affected one person, medical records pertaining to many people have gone missing.

48. I have a copy of **H**'s medical records and I will share these with Thompsons Solicitors.

Statement of Truth

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

Signed _____

GRO-B

Dated 24-06-2019