

ANONYMOUS

Template for written statements – Affected



Witness Name: **GRO-B**

Statement No.: WITN2315001

Exhibits:

Dated: 13th February 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 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 the **GRO-B** 1954. My address is known to the Inquiry. I intend to speak about my mother **GRO-B** date of birth **GRO-B** 1927 and her infection of 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 family and our lives together.

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Section 2. How Affected

2. Mum died seven years ago, in GRO-B 2011. She was infected with hepatitis C after being treated with factor VIII. The cause of her death is listed on her death certificate as pneumonia.

3. Mum was diagnosed with Von Willebrands disease. I was also diagnosed with Von Willebrands disease when I was 5. This is a condition that runs in our family with several family members also having this diagnosis.

4. Mum fell down the stairs around 1981 or 1982 and hurt her ankle and kept having to go into hospital because it kept swelling up. It turned out weeks later it was discovered that she had a haematoma. She started receiving cryoprecipitate and loads of factor VIII at one point because she was being kept in hospital. I worked at the hospital as well and I actually, for a short time, gave her treatment at home as well. I have for the past three and half years been receiving my own prophylaxis because of internal bleeding but I do question how safe this is. The doctors all say *"Yes it is safe... sign here because you also might get CJD"*. I am in between a rock and a hard place. After the incident when Mum fell down, she would always receive treatment in preparation for any procedures for example dental work. I remember after she was diagnosed with hepatitis C she was still receiving factor VIII and I asked her, *"Mum why are you taking the treatment? Do what I do and keep it on standby"*. She said, *"But I am told you have to take it"*, I said, *"No, you have a choice"*. Her response was, *"Do I have a choice really?"* I remember her coming back from the hospital after this from her appointment with Mr Hazard and very excitedly saying *"I did not have my treatment and I was fine. I asked for it to be put on standby like you said"*. She was 65 years old before she knew that was an option. Those were the days when a doctor said what was to happen and that was just accepted. It was a I am God and you will obey mentality. Mum also used to have iron infusions at the hospital as well. The Factor VIII that Mum got was the same as what the haemophiliacs got, the clotting factor.

5. Mum was treated at the Royal Infirmary, Edinburgh, at Lauriston Place and then the new Royal Infirmary at Little France. She was under their care from 1959 with Dr Davies, then Dr Parker, then Dr Ludlam, and then Rosie Dennis.

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6. I think Mum was diagnosed in 1983 and I think I became aware of the diagnosis in either 1983 or 1984. I am unsure exactly about the dates as it was a bit like the secret service getting any information from her. By the time I had moved to **GRO-B** from the Royal Infirmary, I knew about the diagnosis so I do believe it was probably 1983. In my mind she would have received the infected products in 1981 or 1982 as this was when she had the fall.
7. I cannot honestly say I can recall an explicit conversation with Mum about the risks, but I do vaguely remember a meeting at the Royal Infirmary Edinburgh when we were taken into a theatre at the old Royal and vaguely told something about the risks. Even though I worked there I thought, thank goodness, at least this doesn't apply to us, but it was us. It was a big group of haemophiliacs maybe up to 50 other patients told about the possibilities of being infected from receiving these products.
8. The only advice Mum and Dad said that they were given was that if Mum bled, that Dad would have to put gloves on and that they would have to pour bleach over the blood at home. That was the only thing they discussed with me and I have never seen her medical notes. Now I keep things from my dad and I have not discussed this statement with him as I know discussions about everything brings it all back to him and upsets him. His favourite saying now is "*Those days will not come back; they will not come back*". He is 92 and he has been without Mum for seven years now so I do not want to go back and start asking questions about what happened. That would distress him. They dealt with matters, how they dealt with them at the time.
9. There has never been any discussion with me about if the information given was adequate.
10. The only information about the risk that I am aware of is the bleach and blood as I discuss above. Any other risks, I have not been told about.

Section 3. Other Infections

11. As far as I am aware, Mum did not contract any other infections. Her death certificate says that she passed away from pneumonia and dementia. It was old-age basically. Her death was quite peaceful.

Section 4. Consent

12. Mum probably was treated without her knowledge. I was at Penrose and there were two things that just made me shake my head. The first was that the products were not treated or tested until September 1991. When I was pregnant with my daughter, [GRO-B] because I was 36 years old, I opted for amniocentesis. This was in 1991 and then I had to have an emergency caesarean section on the [GRO-B] 1991 because I had severe pre-eclampsia. Both times I was offered treatment. Both times I declined. It was Professor Ludlam then and I always remember this, he wanted us to have a discussion about factor VIII treatment. I declined, because Mum has hepatitis C. I always remember he blatantly looked at me in the eyes said: *"It is ok, it is safe now."* Twice I could have had the product, but I declined it and it wasn't until I was sitting in the Penrose Inquiry, that I heard that it was not safe until September 1991. For someone that can look at me and blatantly lie...it was horrifying. The other thing was that when Penrose said *"You have to remember the doctors were affected as well"*, that was such a crass thing to say to people who have injected their children and then lost them. Perhaps they were upset but it was the wrong forum to say this. There were people there that had injected their children and then their children had then gone to die, it was crass to the extreme. I remember leaving the Inquiry shaking my head saying, I don't believe it, I worked there, how did I not know? Thank God I kept the treatment on standby otherwise I could have had hepatitis C as well.
13. It is possible that my mum was treated without her consent, I can't 100% say for sure. Just knowing the way, the doctors were they had an 'I know what you need attitude', they might have thought, do not give them too much information, they won't understand. It was this whole God complex thing. What is the difference between God and the surgeon? God knows he is not a surgeon.
14. Adequate information was not provided, it was me that told Mum that she did not need to have treatment for a straightforward dental check-up. I remember that she was really excited when she finally said this to them.
15. It is possible that Mum was treated for the purposes of research because having worked in laboratories that they store serum and it's possible that if not at the time, then in retrospect they might have taken it out again and retested it or used in that kind of way.

Section 5. Impact

16. Mum's health was never very good, she always had no energy, her blood count would drop and she would have aches and pains all the time. She always felt like she had to get on with it though. The biggest thing for her was all the plans with her and my dad that they had for retirement. All of these fell apart, she wanted to go travelling, take extended holidays, go on **GRO-B** but her health was never up to it. Mentally Mum would keep how she was feeling hidden. She was upset and angry but her way of dealing with things may have taken the rest of the family into consideration. I have Von Willebrands and my daughter **GRO-B** has Von Willebrands so maybe she thought, I do not want to upset and worry everyone with this. She was always of the 'well there is nothing that you can do about it, you will just have to get on with things, there is no point in crying over spilt milk' attitude. The only other thing I could say is that mum was an old 65, but I don't know if that was hepatitis C related or not. She would have a lot of bleeding episodes in later life. I don't know how much physical deterioration was due to Von Willebrands or due to the hepatitis C, I still don't know this to this day.
17. I don't know about any further medical complications. Nothing has been said to me or written down, but to my mind, the fact that she was paid a stage 2 payment she had further complications, she must have. She would have never received this otherwise. She was told to apply for stage two payments by her liver consultant and she got it no quibbles. Even then, I was not told. To my mind it is what makes sense.
18. Gradually Mum had increasing lethargy, aches and pains. She was often quite pale. She passed away when she was 85. She had dementia and it leaves me with the question of if it was, Von Willebrands or hepatitis C related? That is something they have not faced as well, people with hepatitis C who have lived to a normal old age.
19. Mum tried interferon but I cannot remember if she refused it or she may have had one or two injections and she took really badly to it. She may have tried this in the late 1980s but this is a guess. After that, she would never have returned to the treatment – definitely not.

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20. There were no obstacles to treatment that I know about.
21. I think Mum was offered what was available in the way of treatments.
22. From what I can recall, the treatment itself left her feeling ill. She had no energy and a lot of aches and pains. We noticed that when she was feeling worse then she would snap at people more than she did normally.
23. Mum would go to the dental hospital and they would deal with anything in that area. I am not aware of her been treated differently at all for any other medical conditions.
24. Mum did not speak about hepatitis. She was not well enough to do things though. It was like a hidden thing, you will be ok, you will be fine, that was the attitude. I always remember that Dad got really angry because a relative spoke to Dad and reassured him by saying to him that he would be ok as **GRO-B** got that 'extra' money, referring to the Skipton Fund. Dad's response to that was "*What is money? What does money matter?*" Because Mum did not speak about hepatitis, people would make up their own stories in their mind about how things had played out, they seemed to decide that Mum and Dad were really lucky to get some money. Mum couldn't do anything with it, it might as well have been paper.
25. It wasn't until I sat in the Penrose Inquiry, did I realise how close I came to being infected as well. I had the attitude because of my upbringing, 'these are the cards that we are dealt with and we need to get on with it'. I have no memory of anything being unacceptable. I put my own treatment on hold because I hated needles and I wanted to delay treatments until I really needed it, which happened a few years ago when I had a couple of acute bleeds.
26. Shh, don't speak about it, that was the stigma. She didn't speak about it. That was the stigma. It was a bit like cancer, in those days, you didn't speak about it.
27. Dad was angrier than Mum. My mum accepted it and got on with things. Dad was angry that it had affected their hopes and dreams for the future and dashed all their wishes.

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28. Mum was **GRO-B**. She didn't take a lot of time off work because she was stoical, she wasn't any more ill than anyone else. I remember I was the same because I never took time off work as well. I remember when I was pregnant there was an incident where my gums were bleeding. My normal bleed time is 16 minutes; someone with no condition would have a bleed time of 3 to 5 min. I remember sitting at work and someone saying to me that my gums were bleeding I went up and my bleed time at that point was more than 25 minutes, but I still did not take time off work. Thinking back, if somebody had bumped into me I could have lost my life or **GRO-B**'s life as I was pregnant at the time. But that was the way I was brought up, that was the way Mum dealt with things. She didn't take time off, she didn't become sick all the time. Mum retired when she was 60, which I think was around 1987.
29. I was employed at the Western General, Edinburgh from 1971 to 1976 and then I was at the Royal Infirmary of Edinburgh, employed at the Haemophilia Unit from 1976 to 1983. Afterwards, I was employed at Falkirk for nine years. Then I worked for a period at SNBS making anti-A and anti-B for checking blood transfusions. I then became a science technician at Currie High School and latterly I ran my own counselling business in 2000. I also worked at Stevenson College using my counselling skills. I finally retired on 30 June 2011 so I worked for 40 years.

Section 6. Treatment/Care/Support

30. The Haemophilia Centre at the Royal Infirmary in Edinburgh were fine. They were always there for you and they have always been like that. You just turn up and they will deal with you. There are no delays. I took psychological support up after Penrose, but there was nothing like that until a couple of years ago, by which time Mum was already dead. I don't believe it is adequate but she was never offered psychological support.

Section 7. Financial Assistance

31. I don't know about how Mum found out about the financial assistance for stage one, but certainly for stage two it was a liver doctor who was part of the haemophilia clinic who told her to apply. Dr Dennis signed the forms for her. They got her help to fill the application in but I can imagine it was different to a stage one application. It is not something I can imagine

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she would have dug around for information on though so it was likely that she was approached.

32. I believe she received £20,000 from the Caxton fund and then £50,000 for stage two. Before she died she was getting £1,340 every month, but when she died that stopped. Two years ago, Dad could have got this again in April and I asked the people from Haemophilia Scotland if he could. They said no because hepatitis C is not on your mum's death certificate so your dad will not get any more money. In November 2017, I was looking at this further and I contacted the Scottish Infected Blood Support Scheme and that information was incorrect, as a result, he is now getting £1,670 a month because he is mum's widower. Once a year, he has to sign a form and confirm that he is still alive and has not remarried or anything because if he ever did, he would lose the support.
33. I don't know the process of applying for financial assistance. I didn't help Mum fill in the forms for hepatitis support, I would have remembered that.
34. I don't know if there were any obstacles as I was not involved in applying.
35. Dad likes that he is getting the money now, he calls it 'Mammy's money'. He gets the money on the 15th every month. 'That's your mammy's money', that is what he says. That is the link back to her. Whenever the form comes in, he is always worried that he will lose the money. I try and reassure him by reminding him that this is just a legal thing that they are doing but he is always worried if the money is going to be there or not, in his bank account. It was December 2017 when he started getting the money it was backdated to November as that is when we applied. I could have got this for him from April 2017, however, I was given wrong information from Haemophilia Scotland as I discussed above.
36. I remember when Mum went into a care home we got a visit from the DWP. The money that we received from the funds caused issues with them. They were saying that Mum's compensation had to be included when we applied for any benefits. I said no, as it was compensation that this was money she is entitled to. They said yes, but it needs to be included when applying for any benefits. I had a letter from Caxton for Edinburgh Council explaining that the compensation was to be disregarded. We were previously told by the Care Inspectorate that her compensation was like Attendance Allowance and the money should be used towards paying for her care. I think this is ridiculous, this was when applying

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for guardianship as we were too late to apply for P.O.A. due to her dementia. They were saying that there would have to be a whole procedure involving a visit from a doctor and handing in accounting books every year to apply for guardianships. Mum died three months later, so we did not go any further with the lawyers in applying for guardianship, we didn't want that to go through anymore.

37. Mum got stage one and stage two payments, but they were too ill to do anything with the money. They should probably be properly compensated, but the bigger picture is that some people have not got anything, which is totally unfair. David Cameron stood up and promised that there was going to be something like 25 million or something support for everyone. I do not think we have seen that yet. Kick things far enough down the line, is everyone going to be dead and it will all be forgotten? No amount of compensation will bring a loved one back but for somebody to be suffering because they cannot work and they cannot get support, it is crass.

Section 8. Other Issues

38. Psychological impact. After sitting in the Penrose Inquiry and hearing that twice I could have been infected, seen grown men cry and crass statements about other doctors, I remember being really upset. About three weeks after the Inquiry I had an acute bleed and I think it was because I got so upset. I cannot pin it down exactly but it makes me think that that is what was behind it. Psychological support was offered about a year after this and I remember saying to a counsellor "*I could have done with you six months ago*", because I was going through a lot. I was waking up crying and distressed, I could not sleep, her response to me was out of order it was "*But that's in the past now*". I remember inside thinking, for you maybe but not for me. I think that is what happens a lot with hepatitis C. 'There is some money', let's move on, but it doesn't go away. I injected my mum a couple of times and it could have been me they gave her the infected products to. Can you imagine doing that to your child?

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39. Thompson Solicitors are recovering my mum's medical records for which I will be given an opportunity to review.

Statement of Truth

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

Signed GRO-B

Dated *28th February 2019*