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Witness Name: GRO-B

Statement No.: WITN0483001

Exhibits: nil

Dated: 25-01-21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 04 February 2019

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1982 and my address is known to the Inquiry. I am a chartered accountant and I am currently employed in an accountancy firm. I am happily married and have two children.
2. I intend to speak about my husband's infection with the Hepatitis C virus (HCV), which he contracted as a result of being given contaminated blood products to treat haemophilia. (His statement to the inquiry is WITN0007001).
3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment received and the impact it had, particularly on him as I saw it and our lives together. I do not wish to detract from the

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suffering my husband experienced so will only speak in a limited capacity about the impact on me.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. My husband and his brother both have haemophilia. His brother is also infected with HCV. Much of what I will say has come to me from my husband and his family members as I did not meet him until the year 2000.
6. My husband was diagnosed with haemophilia A at 2 years old and started factor treatment around 3-4 years old.
7. As a child he had regular infusions of concentrate and spent a lot of time in the Royal Victoria Hospital. Being one of six children meant there was a lot of rough and tumble growing up.
8. Dealing with haemophilia as a child made it difficult for him at school. Teachers would overreact about a bleed, children would not involve him in activities, and he was labelled a bleeder.
9. He suffered with particularly bad nosebleeds and in 1991 was blue lighted from GRO-B to hospital in Belfast after using two boxes of tissues following a particularly bad event. I am aware that he was given a blood transfusion, and this is the only occasion where he recalls having one.
10. He has told me that there was a lot of medical interest in his blood during his early years. The haematology centre would arrange frequent appointments to take blood.
11. Over the years his severity of haemophilia has changed, from severe to moderate. The severity should have remained consistent throughout.

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12. According to medical notes, the first admission from the NHS that he had HCV was in 1991. My husband was not told at this point. Interestingly, liver function tests were taken regularly prior to 1991. This makes me think; did they suspect it? He was extremely lucky to locate his medical records as most have been destroyed, I believe, as part of a cover up. I know he had to fight long and hard to get that access
13. He tells me the infection was then brought up again in 1995. He was 15 at the time and weighed only 8 stone. His parents were informed not to tell him that he had HCV by Dr Dempsey, the haematologist at the time. They were told not to worry too much and that it was just a little bug in his blood. They should never have been put in this position. It seems to me that the doctors happily buried information, despite knowing the risks there and I ask myself; was this related to them knowing earlier in 1991?
14. His brother was getting engaged to be married at the time, so was informed he was infected with HCV. I think this is the only reason the parents were told about my husband as well. It is concerning my husband himself was not made aware. He could have been sexually active at the time, so it seems they were happy to let the infection spread.
15. My husband actually became aware of the infection when he was 16. He was given no information of how to manage the virus and the precautions to take. No sexual guidance was given.
16. We have no indication of when my husband received the infected product and cannot find anything in his medical notes.
17. I know Dr Main was the haematologist he saw as a young adult, but he now sees Gary Benson. He has been his haematologist for at least a decade.

Section 3. Other Infections

18. My husband has not received any infection other than HCV as a result of being given infected blood products as far as I am aware.
19. I recall he received a form in relation to a risk he may have contracted vCJD. He returned it to say he did not want to know if he had vCJD. There is no cure and once the disease starts to surface there is no hope. I can understand his feelings on this as I have witnessed first-hand the trauma caused by the symptoms of his HCV and the medication prescribed to him to clear it.

Section 4. Consent

20. I was tested for HCV in 2011 but I was not informed that the blood taken was to be used for that purpose. I was found to be negative.

Section 5. Impact

21. My husband developed severe OCD and anxiety as a result of his infection with HCV. He became very conscious about cleanliness to the point of obsession. GRO-B: H would use Dettol on everything he touched. Everything had to be spotless. It could lead to arguments and tension between us. I remember that whilst infected he sometimes showered up to 4 times a day on average.
22. I know he started a 9-month course of interferon and ribavirin to clear the virus in 1999. It was horrendous and the only side effect he did not experience was hair loss. H lost a lot of weight and his appetite went completely. It was at this time that we first met.
23. Dr McNalty, the research haematologist specialist knew the liver function levels were still through the roof after the first treatment. H was not

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told straight away that the treatment had not worked, and he was made to wait 5 weeks before finding out. I can't imagine the strain of going through what he did and then having that wait to find out if it had been successful or not.

24. The second course of combined treatment started in 2004/5. Again, I believe it was 9 months duration and consisted of tablets and injections into the stomach. [H] had to take a 3-4 week break from taking the medication as he became so ill. He had no appetite, was constantly sick, and suffered with extreme fatigue. I looked after him at the time and the stress was immense. The emotional impact of seeing the man you love suffering and knowing you can do nothing to help, other than provide comfort, is debilitating. I had other commitments but my main priority was [H]. The hospital was receiving positive results from the treatment that he was fighting the virus, but he could not continue with the treatment despite all our best efforts.
25. Following his break, the treatment resumed and the viral load cleared in 2005/6. He has been told that it will not come back but we are unsure if the virus can be completely eradicated. That thought is never far from my mind.
26. [H] until recently has never had a liver biopsy and was consistently told it is too dangerous for haemophiliacs. We had researched it and knew it could be done and he has had and survived hernia operations in the past, so found the refusal of a biopsy concerning. There were other methods available that don't require cutting into the liver. He has now had a Fibro-scan but I have to question why it all took so long. We always seem to have to fight for what really should be offered as part of the treatment and management of a condition that he contracted through no fault of his own.
27. He used to be seen every 3 months to have a blood test, but this has been reduced to every 6 months.

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28. My husband kept quiet about the infection when we first met, he felt it would not have been the best introduction. It is a strong example of the stigma he felt was attached to the HCV. Did he risk losing me by telling me about it straight away? It is a difficult dilemma to manage for anyone. I understand now but had no knowledge then, just like the majority of the public in general.
29. [H] had to stop working 10 years ago to look after me. I was diagnosed with Antiphospholipid Syndrome, a clotting disorder. I had my first clot when I was 18 in my leg, and then in my lung in June 2001. In 2010 I had a clot in my liver whilst pregnant. Our son was born early and I was given a liver transplant. I was not expecting to survive. 21 days after the procedure I was told it had not worked, so had another liver transplant.
30. The haematology unit at the Royal Victoria Hospital became a second family to us. When each of our children were old enough we took them in to meet the staff.
31. Our children do miss out because of [H] infection with HCV and due to his haemophilia. Even going out for a walk or taking them swimming is difficult. He still suffers from a lack of energy. However, they have known no different, and have grown up with the health issues we both have. They have learned to adjust and for that reason the actual impact on them is difficult to quantify.
32. My husband feels guilty about my health conditions as they spontaneously arose. I have reassured him as have the doctors but I know the guilt remains and this is painful for me. I was perfectly healthy when we met and for some years after, as mentioned and then everything started to happen. I have been told that my condition is not stress related but I do wonder if the constant worry and anxiety over the years have contributed to it.
33. During the course of my husband's second interferon treatment, I was working full-time and studying for my Charters for Accountancy. I pretty

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much failed all of my exams that year, due to the stress. I was an emotional mess throughout the 9 months of the treatment and would find myself breaking down or crying most days. Looking back, I can see that it was due to the stress and the worry for my husband, then fiancé. It took me a long time after the end of the treatment to get my emotions and stress under some sort of control.

34. The health service has decided there is no longer any need to worry because [H] has cleared the HCV. I feel so hurt and angry that they can act like this, and not fully realise the extent of what they have done.

Section 6. Treatment/Care/Support

35. [H] has never had any treatment refused that I am aware of.
36. I strongly believe there should be so much more medical follow up for people who have been infected with HCV. I have far more appointments for my own health issues. The government should ensure the NHS provides aftercare, as they are responsible for this. We had no idea in regard to possible damage to [H] liver due to the failure to conduct the relevant tests until recently. He has now been provided with a Fibro-scan. The outcome was given to [H] as no tumours noted.
37. I find it suspicious how the haematologist research consultant Dr McNalty retired before the scandal was exposed. She went off sick and retired straight away. She never wanted to listen to our concerns. I am sure Elizabeth Main also knew what was going on but this is just a feeling as how could they not have some inkling that something was wrong with the virus affecting so many people?
38. Before the Inquiry started my husband was seeing a psychologist at our local hospital for his OCD and anxiety. However, since the Inquiry started the haemophilia department has now got a psychologist working closely with the infected/affected people. My husband has been seeing her for the

past 12 months. I also believe that psychological care should be offered to those infected at the time they are given the diagnosis and it should continue into treatment. The medication used throws up its own mental health issues but it was left to myself and the family to deal with that. Furthermore, why was there no support of that nature on offer for those having to deal with the fallout? Why did it take 25 years to be put in place?

Section 7. Financial Assistance

39. We became aware of the Skipton Fund in 2001 through the haematology centre.
40. My husband applied directly but much of the application process was completed on his behalf.
41. A one off payment of £20,000 was granted for being infected with HCV through contaminated blood products. Conditions were attached to the payment and my husband had to sign a disclaimer prohibiting further entitlement and waiving liability of the health service.
42. The haematology centre instructed him to accept the payment because he might not be entitled to anything else.
43. My husband did receive an additional £5000 from another fund but neither of us can recall who it was.
44. We now receive £1546.33 a month from the Belfast Health Organisation (BHO). This is our only income, other than state assistance at present. The amount of money prior to this, just over £340 was an insult considering the trauma and suffering experienced by my husband and by extension our family.

45. We are now in a vicious cycle of benefits because I can only work part time due to my health. I have always been career orientated and as stated, am a chartered accountant by profession.

Section 8. Other Issues

46. I think the contaminated blood scandal is still buried and to this day the NHS is not transparent. I recall the whole city hospital shutting down for a month in the summer to get their paperwork in order. Was this because they may have to answer to the inquiry?
47. I would like to know why the pharmaceutical companies are not taking responsibility and why no one is holding them accountable. They have far too much power, which is the problem. They should be paying out to those infected as they supplied much of the contaminated products.
48. It is wrong that compensation payments are coming from the health service. Money should not be taken from them, as they need on-going financial assistance. The compensation impacts research and development as well as general patient care.
49. Furthermore, the compensation given to us in Northern Ireland always seems to be less. I know it has improved now but it is as though we are not as important. Any compensation payment should be consistent throughout the UK.
50. My husband is very paranoid around doctors as a consequence of the contaminated blood scandal and his subsequent treatment by the medical profession, where they have not been transparent with us regarding his medical conditions. My faith in doctors has been sorely tested throughout this time. I feel that from now on I will always request a copy of results and so forth because I do not fully trust how this information is presented to us by doctors.

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Statement of Truth

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

Signed GRO-B

Dated 25-01-21