



Witness Name: GRO-B

Statement No.: WITN2215001

Exhibits: N/A

Dated: 26th 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 5th November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B
1963. I am married to my husband GRO-B We have eight
children. These are GRO-B
GRO-B and GRO-B I had to give up work because of my ill health. Prior
to giving up work, I worked with children with special needs in a local
primary school.

Section 2. How Infected

2. I believe I was infected with anti-D vaccinations. I received these after the birth of three of my children in GRO-B 1986, GRO-B 1987 and GRO-B 1988. I was treated by a Dr GRO-B for all three of these pregnancies. The only reason that those three required the anti-D vaccination was because their blood was O positive and mine is O negative. I was not aware that the anti-D product was a blood product.

3. I received the anti-D vaccination on GRO-B 1986 after the birth of GRO-B. I also received an anti-D vaccination on GRO-B 1987 after GRO-B and on GRO-B 1988, after the birth of my son GRO-B. I am aware that the notes are only still available for GRO-B and the notes prior to this have been destroyed.

4. I found out about having hepatitis C on 11th August 2014. I received a letter from the Royal Victoria Hospital in Belfast. I had recently been diagnosed with rheumatoid arthritis and in order to get the biological treatment that they were going to give me, this required a blood test. The blood test was in March of 2014. I was not notified about having hepatitis until the August of 2014. I feel that that was six months where my infection was overlooked.

5. It was in the letter that I received on 11th August 2014 that said that I had shown up as positive for having hepatitis C. This letter said that I would be put on the waiting list in order to find out any more about my condition. I ended up going privately to a liver consultant. I was treated six months after my private medical appointment.

6. This letter did not give any information about hepatitis C nor did it give any indication of what the timescale was for me seeing someone at the NHS. They only said that there would be a wait.

7. When I went to my private medical appointment, I was told more. They said that my genotype was five and that they had never treated this in Ireland before. They said they did not know how to treat this. They said that only 0.1% of people have this type of hepatitis C. They said that they would have to give me what they referred to the old 48 week treatment of interferon and ribavirin.
8. The letter I received was completely out of the blue and offered no explanation. The information given was entirely inadequate.
9. I contacted my GP after I received this letter and he referred me to a Dr Cash in the Royal Victoria Hospital in Belfast. It was only when I was privately treated that I got more information about hepatitis C. They said that my children were at risk and that they all had to be tested, as well as my husband. All of these came back as negative.

Section 3. Other Infections

10. I was infected only with hepatitis C genotype 5.

Section 4. Consent

11. I recall that they took my blood during my pregnancies and they never detected anything as far as I was told. My son, GRO-B, had leukaemia and we were all checked for our bone marrow. I asked at the Royal Victoria Hospital in Belfast and they said that they would not have checked for hepatitis c when doing this.

Section 5. Impact

12. Prior to my diagnosis, I did notice over the years that I had flulike symptoms. I had no energy and I had no 'up and go'. I suffered from

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fatigue and I could sit at a table and fall asleep. I suffered from brain fog and would sometimes get mixed up in conversation. Sometimes when I was driving, I had to think of being on the right road. I started noticing these maybe five or six years ago.

13. I do find that I have been more prone to colds and flu and there were times where I would be in my bed for days. I believe that I may have developed rheumatoid arthritis through one of these viruses that I had when I was having more colds than flus. I do believe I was probably more tired than I should have been at the age I was. I put down my tiredness to the stress of having a terminally ill child. I have had a lack of appetite over the last 10 or 12 years and have been underweight at times. There are nights when I would go to bed and be lying down and I would have to get up and vomit. This has been ongoing for years. I also feel the cold more and my heating has to be on all the time.
14. I was diagnosed as having rheumatoid arthritis in October of 2008. I did have aches and pains prior to my diagnosis but they got so bad that I had to go and get it looked at.
15. In terms of any other medical problems I have had as a result of my infection, I would say that I have had issues where I had been anaemic for a number of years. I had to go to City Hospital for iron infusions. They kept giving me that. My liver was also checked and has been up on a number of occasions. This was checked prior to my hepatitis C diagnosis. This was within the last 10 years. My liver count was up every month and I went to my GP. I am not sure of what the levels were. I have not diagnosed with cirrhosis.
16. The treatment I received for hepatitis C was interferon and ribavirin. This was successful. I recall that week one started on 24th June 2015. This was a 48 week course. I would have interferon injections once per week and ribavirin pills every day. The first treatment was at hospital and then the rest were at home. Because my blood was so low, I did

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have to go to hospital every week in order to have my injections though. This was to the Royal Victoria Hospital in Belfast.

17. One of the early barriers I faced to treatment was that I was on a waiting list to be seen by the NHS at the start when I got that letter. The only indication of time it gave was that I would be seen in the near future.
18. I was hopeful one stage for what they refer to as the new 8-week treatment but they said they had never treated anyone with genotype five with that treatment. They never said what this treatment was called, they just said it was a new 8 to 12 week treatment.
19. In terms of my symptoms following that first dose treatment, I noticed that the next day after the injection I could not walk. My legs went from under me. They had informed me that my muscles might be affected. At one stage, I was having heart palpitations and had to get put on a monitor.
20. My flulike symptoms got worse while I was on treatment and I felt that I was in bed for six months, other than when I was in hospital. I struggled a lot mentally during this time when I was on treatment. I remember about 22 weeks into treatment I said that I could not go on but I did continue on in the end. I believe I have suffered from depression and I have gone to a low point before, but I did not need medication.
21. I have not noticed any difference in treatment when I am in hospitals. I never told anyone beyond my family. I do believe they see a sticker on my form but all medical staff have been fine. I felt that a lot of them did not realise about my condition until I told them when they were treating me. I told them when they were not wearing gloves. I do not believe my condition has had any impact on dental treatment.

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22. In terms of my family life, I would say that it has been a terrible worry when the likes of the children had to be tested. The wait to find out was an absolute nightmare. If they had had it, it would have been worse than having it myself. I felt I did not have the same energy as other people. I kept pushing myself and wearing myself down. I was not involved in after school activities other than picking my children up. I may have been had I had more energy.
23. My social life was non-existent as far as going out. I just did not go out at all. I did not have the energy. I often had to cancel plans, like going to a wedding, last-minute and things like that. It was hard to know what to say, especially when I was not diagnosed yet. I feel that my social life has been improving in the last six months and it has been a big change. When I found out, I did not want anyone to know.
24. The stigma of having hepatitis C has had a big impact on me. The first initial impact was my fear of my children being diagnosed with having it as well. When I found out about my hepatitis C, they were already in professional jobs or at university. I was not even aware of hepatitis C prior to my diagnosis. When you get the anti-D injection, you are not made aware of what it actually is. No one ever said it was a blood product. They just said that you had to get it. No one ever said at any point there was any risk when having the anti-D vaccination. I just thought it was a manufactured medication.
25. When I first went to the Royal Victoria Hospital in Belfast, they said that there was a strong possibility that I had HIV. I was tested for that as well and it came back negative. That was the biggest shock of all. I thought my life was never going to be the same again. It was a massive relief to know that I did not have HIV. The doctors were so casual about it as well and they had no bedside manner. It felt that they did not realise the impact of what they were talking about. I think it was just another blood test to them.

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26. I believe my daughter GRO
B's education was possibly affected by my treatment and condition. I remember that she had her A-levels during my treatment. It think there was a big stress with everything going on at home. She was so worried about me. I was so unwell at the time, I did not realise. It was probably different for those who were at University; they had already done their exams.
27. I stopped work in 2008. I had to stop because of rheumatoid arthritis. The board said that I was dismissed on health grounds. My role was as a special needs assistant. I had done this job for four years beforehand. I definitely would have continued in my job had I been more physically able. I really needed the social aspect my job as well.
28. I received DLA for 10 years but they assessed me for the PIP payments and stopped my mobility benefit. In terms of benefits, my doctor did say to go on DLA., they came out to assess me. They said I didn't fit the criteria. They said I was not unwell enough for mobility and that was the end of things.
29. It has been a big impact financially not working. The impact has been financial and social in terms of work. When I worked I had money for myself.
30. I do have life insurance but I have not notified them or my home insurance about my condition. I remember Dr Cash saying about travel insurance, that I did not have to declare my condition when I was cleared. I do have to reveal that I have arthritis though. I have not travelled since I was diagnosed. There has been no direct impact on my mortgage.
31. My husband is self-employed and I feel that this has been a massive strain on him. He would need time off to take me to hospital because I did not drive and he had to run the house and look after the children as well as me. It was a major financial burden at that stage. I had trips to

the hospital every week. My husband's job is making kitchens. He had to turn down work at times while I was ill.

Section 6. Treatment/Care/Support

32. At no stage was any counselling or support offered. I think that it would have been helpful. I remember a nurse spoke about it at one point and I was checking stuff for myself on google. Nothing was offered, it was very much inadequate.

Section 7. Financial Assistance

33. Dr Cash said that it was his duty as a doctor to give me the form for the Skipton fund. I was turned down on two occasions and they said that anti-D was considered to be safe. They turned me down completely. I have received nothing from the Northern Irish government. This has been totally inadequate. It cost us every day to go to Belfast and I believe that some days that would have been £50 at least. I also had to pay for private treatment and those were £180 each. I believe I went for two private treatments.

Section 8. Other Issues

34. In terms of the Penrose Inquiry, I did read about it. It seemed that they would not admit the mistake on the part of the National Health Service.
35. I did consider looking into litigation but when I went to a solicitors firm in Belfast they said it be too expensive for me to pursue this.
36. I would like my statement to be anonymous as I have children in public health jobs and I do not want it to affect them.

Statement of Truth

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

Signed

GRO-B

Dated

30/3/2019.