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Witness Name: GRO-B

Statement No: WITN2417001

Dated: 15th January 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 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, GRO-B will say as follows:-

1. Introduction

1. My name is GRO-B My date of birth is GRO-B

GRO-B

2. I live at this address with my husband GRO-B

GRO-B

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3. I intend to speak about my mother [GRO-B: M] infection of hepatitis C, which she contracted from a blood transfusion or blood products in [GRO-B]. In particular, the nature of her illness and how the illness has affected her, the treatment received and the impact it has had on me.

2. How Infected

1. My mother has a rare blood condition, Haemophilia Factor 8,9 and 11. Although I we didn't know at the time, my mother contracted the hepatitis C virus when I was about [GRO-B] years old. She had a [GRO-B] operation and because of her condition she was given a blood transfusion plus blood products which were infected with hepatitis C.
2. I can remember my mother being in hospital for a long time. I was a poorly child as I also have [GRO-B]. My grandmother had to look after my [GRO-B] [GRO-B]. Throughout my childhood my mother was often very tired and would be jaundiced and too poorly to look after us. I remember she visited the hospital lots of times and she would tell us she had to go, as she wanted to get better so she could play with us.
3. When I was about [GRO-B] I can remember my mother telling us not to share toothbrushes or towels anymore. Before this I would use my mother's razors to shave my legs and she said this wasn't to happen anymore. I asked her why and she said the doctor had told her this is how it is to be from now on. From that moment on my mother was constantly cleaning the bathroom and the rest of the house with disinfectant. Since then she has been obsessive with regard to cleanliness and worries about things not being clean.
4. Over the years my mother has been poorly and she has always wanted to get to the bottom of why she was so ill. I am aware that doctors often told her she was depressed and not to worry about anything, or any of the symptoms she was getting. She would often come home upset, as doctors would often dismiss her questions. This still happens today. There were regular

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occurrences when her Consultant did not make appointments or she would get forgotten about this often upset her as it further prolonged any diagnosis. At different points there were various conditions mentioned to her in terms of what she was suffering from including Autoimmune Liver Disease.

5. In [GRO-B] my mother and her husband [GRO-B] went to live in [GRO-B]. It was an exciting time for them both because after bringing up [GRO-B] children her life was starting afresh. It is common policy for anyone outside the country going to live or work there to have blood, urine and faeces tests carried out. I remember my mother and [GRO-B] telling me that the work's doctor informed them that my mother's results had come back showing she had hepatitis C Antibodies. This was very upsetting for them both as my mother was immediately issued with an Exit Only Visa.
6. When my mother returned to the [GRO-B] she went to see her GP to show him the results she had received in [GRO-B]. She was referred to [GRO-B] [GRO-B] for a liver MRI scan. After this, the GP arranged for her to go to [GRO-B] Phlebotomist department for specific blood tests for hepatitis C.
7. I remember my mother telling me in early [GRO-B] that she had received a telephone call from [GRO-B] he had found evidence she had been infected with hepatitis C through the blood product transfusions she had after having the [GRO-B]. He had managed to trace back the number codes on the infected blood that was transfused to her.
8. It wasn't until [GRO-B] when my mother finally had confirmation she had contracted hepatitis C through contaminated blood product transfusion(s). This was through a letter she had from the Skipton Fund awarding her £20,000 and a monthly allowance.
9. I know since finding out, my mother has asked her Haematologist why she was never told about contracting hepatitis C until it was confirmed in [GRO-B]. He told her he didn't want to say anything to her, as I was very ill at the time when they found out.

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10. We have since learned the consultants knew as early as [GRO-B]

3. Other Infections

1. As far as I am aware, the only infection my mother has contracted through the contaminated blood transfusion is the hepatitis C, PCR Negative.

4. Consent

1. Through discussions with my mother I am aware that when she had her [GRO-B] the risks were not explained.
2. I believe my mother was tested for hepatitis C by her request due to the findings in [GRO-B]. She was never informed of the reasons why she was being tested and for the medication she received. I now believe the medical professionals looking after my mother's health care knew about her condition as early as [GRO-B]

5. Impact

1. It has been a horrible experience for my mother and has been a challenge for her over the years to get a firm diagnosis. She has always been determined to get well and will challenge every health complication she gets due to being infected with hepatitis C.
2. I can remember it was knocked about for a number of years, [GRO-B] whether she had contracted hepatitis C. Is she, isn't she? It was a relief for my mother to finally have it confirmed as the medical profession put her symptoms down to other conditions including depression, almost as if she was making it up.

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3. My mother is a master of disguising her true feelings. Certainly the social aspect has had an affect on her as she feels she will branded unclean and she always feels unclean.
4. My mother is constantly tired and suffers with other complications that have resulted from being infected with hepatitis C. She has fatty liver disease with cirrhosis and has to have regular liver assessments the last one scored 2.5 which was lower than any other score she has had and she is worried that this hasn't been done properly. She also has Chronic Kidney Disease and MGUS (Myleoma). In addition to this, her consultant has also informed her, she has type two diabetes. Although, my mother's GP does not agree with the consultant and this is an added worry for her as she cannot attend the Diabetic Clinic. My mother is currently undergoing tests for masses detected in her breasts.
5. My mother has to take a lot of medication. Because of the side effects as well as her condition she declines invitations to go out on social events with family or friends. My mother is often in a lot of physical pain due to her liver condition as this is now at the end stage.
6. I am a **GRO-B** and due to my profession if my mother cuts herself she will not allow me to help her. It can only be her who cleans up any blood and it will take her a long time to clean it up until she is satisfied it has all gone. She does it in this way as she has to be certain no one can contract hepatitis C.
7. This has affected my children in a social way. My mother cannot attend any school events like ordinary grandparents do, because of the side effects of the medication she takes.
8. Since my mother has learned of contracting hepatitis C certain family members refrain from any physical contact with her and she will not kiss my children or me assumingly due to fear of us catching the disease.

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9. I believe this has impacted on both my mother and [GRO-B] financially. [GRO-B] has had turn many jobs down in the [GRO-B] because my mother couldn't accompany him. My mother's condition also has an impact on home and life insurances too as they cost more because of the hepatitis C. The condition of my mother's liver now determines how warm she has to keep the house, as she gets very cold, impacting on them both financially. My mother worked as a [GRO-B] she enjoyed this job very much, but had to leave due to the symptoms she was getting through hepatitis C. I am aware my mother and [GRO-B] had to re-mortgage the house in order for them to both live.
10. During my childhood I cannot remember ever playing with my mother. She was always very ill and tired most of the time. I would often go to my friends to play but friends couldn't come to my home as my mother was too ill. I took on a young carer's role, looking after my mother and I become very protective over her. I had to spend a lot of time with my grandmother when my mother was ill and this affected me greatly as I too would become ill if I had to be away from her, my mother's illness also affected me psychologically and I missed a lot of school because of this. We have never been able to do normal mother and daughter things.
11. My mother won't tell anyone outside her immediate family about her condition. She feels she will be branded.
12. I am always worried about my mother's health. Now she is in the Stage 2 phase her health is getting poorer and she is in a lot of physical pain as her liver has got worse.

6. Treatment/Care/Support

1. As far as I am aware, the only confirmation from any doctor my mother had about having hepatitis C antibodies was in [GRO-B] when she had results from tests taken in [GRO-B]. It took another eight years when it was finally confirmed and this was through the Skipton Fund.

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2. My mother has not been offered any counselling or support, in fact whenever she asks a consultant or GP about any complications resulting from contracting hepatitis C, she is often dismissed or told not to worry about a thing.
3. There is a lack of communication due to my mother's health care being crossed over to different hospitals. She has to go through the whole story every time she is at a hospital whether it is a procedure or blood test. My mother often finds herself having to defend herself because either the medical practitioners haven't read her notes or they have a lack of understanding regarding her condition. One other thing she does not like is when her notes have been read and there is a big sticker with danger of infection written on in big writing. This makes her feel humiliated.
4. There has been no face-to-face consultation with medical practitioners where my mother has been formally told she has hepatitis C. In fact any face-to-face consultations have been very vague and too complicated to understand. My mother is often dismissed when she enquires about symptoms and told not to worry about that at the moment. This in my own professional opinion has a detrimental affect on the patient/medical professional relationship. I have often had to Google abbreviations such as protein (light chains) as this wasn't explained in a way we could understand. Since my mother became aware of her diagnosis she often gets conflicting advice on danger and risks when she asks about this. I accompany her to all hospital appointments now in order to fully get the information she needs. I will ask questions and make sure things are explained. I have to sometimes change my shift pattern in work so I can attend with my mother. My mother finds the whole thing very intimidating when they talk in laymen's terms or above her. She doesn't cope very well, she feels like she doesn't deserve to be there, and she doesn't!
5. My mother has been prescribed antibiotics since GRO-B which she takes when she feeling unwell. She has a very large prescription for the following medication for complications that have arisen due to contracting hepatitis C:- Metformin, Tramulief, Tranexamic Acid, Oramorph, Butec, Amoxicillin, Diazepam,

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Furosemide, Loratadine, Lansoprazole, Amitriptyne and Crestor. I believe Interferon/Ribervan wasn't offered to my mother due to cost and post-codes.

6. I have never been offered counselling, information or support and because of my condition of **GRO-B** I often get worried if I have contracted anything through blood transfusions or blood products I have had. I have received a letter in the past, possibly around **GRO-B** years ago, with regard to some blood which had been infected with CJD that may have been transfused to me. To the best of my knowledge, I am on a database of people who may be affected, as is my son **GRO-B** who has never received blood or blood products. Therefore, information being received still remains unclear and confusing. My blood was okay but I do worry if like my mother, a positive result is being kept from me.
7. My mother, as far as I know, wasn't treated for hepatitis C as she was never told she had the condition even though they knew about it as early as **GRO-B**. If she was treated it was without her knowledge and consent.
8. My mother carries a Haemophilia Card but it does not say anything about hepatitis C. This concerns her because if she needed urgent treatment she feels she may infect someone. She now carries with her letters from the hospital where it states she has hepatitis C in an envelope marked 'Open in case of medical emergency.'

7. Financial Assistance

1. My mother by way of the Haemophilia department applied for the Skipton Fund London and her application was turned down. I remember my mother telling me her consultant said at the time, she wouldn't get the fund because she hadn't got hepatitis C. I believe the Consultant had informed them that she had cleared the hepatitis C virus without the use of past or on-going interferon based treatment and without radiological or pathological evidence of chronic infection after the acute phase.

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2. The decision to appeal was made after [GRO-B] read my mother's notes. It wasn't until [GRO-B] she was awarded £20,000 and a monthly allowance of £385.17.
3. My mother has recently made an application through the Velindre NHS Trust for the second stage award.
4. When disability living allowance was changed to personal independence allowance my mother had to be assessed. I think she had to do a few tasks such as hold her arms up, walk in a straight line and because she could and didn't have a mental illness the allowance was stopped. She later appealed and now gets the full rate.

8. Other Issues

1. I would like to see the outcome of the inquiry to recommend that in the future there is more information offered to sufferers and their families and these people have the opportunity to be educated i.e. if they ask questions they should be answered in a way that can be understood.
2. In regard to receiving blood and blood products, I think informed consent is currently brushed over. What is the point when people are informed there is a risk, if it's a matter of life or death and a blood transfusion needed, would anyone consider the risk? I would like the Inquiry to recommend improvements to education for the general population on the benefits and risks of receiving blood and blood products. This decision is often made in an emergency situation. I personally feel this is not an appropriate time for an individual to be hearing the risks to receiving transfusions for the first time and then be expected to make a decision.
3. I would like the Inquiry to learn from each case and individual learning merits.

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4. There should be a national computerized database held by the UK NHS in order to ensure swift responses to diagnosis, emergency care etc. can be communicated effectively. I believe that an individual's medical records should be equally the property of that individual and the Health Board. Access should be 100% open and transparent to the individual.
5. Finally, if my mother did not have that transfusion in GRO-B I wouldn't have her now.

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Statement of Truth

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

Signed...

GRO-B

Dated... 15/1/19