

ANONYMOUS

Witness Name: **GRO-B**
Statement No: WITN2579001
Dated: 20th March 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** make this statement true to the best of my knowledge and belief and will say as follows: -

1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is **GRO-B** I currently live with my partner and our **GRO-B** year old son.

2 How Affected

1. My mum, **GRO-B: M** had a hysterectomy in **GRO-B** at the **GRO-B** **GRO-B** **GRO-B** during the operation she was given a blood transfusion.

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2. There was no information or advice provided to me or my mum beforehand about the risk of being exposed to infection.
3. In GRO-B nine years from my mum's hysterectomy operation, she received a letter from her doctor stating that she may have contracted Hepatitis C from the blood transfusion she received. She then went for blood tests and a biopsy. She then went to her GP who told her she had Hepatitis C and informed her that treatment would be necessary. Further tests revealed that she also had cirrhosis of the liver.
4. When my mum found out she had Hepatitis C from her GP there was no further information provided to her other than she would need treatment, they did not tell her of any details of these treatments she would need or how they could have affected her, he just referred her to a Consultant. She was told very little at the time.
5. Once my mum found out she had cirrhosis and knew she would have to go for treatment and further tests, she felt compelled to tell her family as she was unsure about her future. She told us very little. We were not given further information from anyone else and no information at all about the seriousness of the infection or the possibility of it being passed on to anyone else.

3 Other infections

1. As far as I am aware, my mum was not infected with any other infections other than Hepatitis C.

4. Consent

1. Since my mum was diagnosed with her infection she has always been told when and why medical staff are taking her blood or giving her any treatments. I am not aware of them treating or testing her without her knowledge.

5. Impact

1. I think that the diagnosis of Hepatitis C has had a serious impact on the mental and physical health of my mum. Mentally she never stops thinking about it, always a constant worry about her future. My mum has suffered from periods of depression. She was diagnosed with cirrhosis and since then she has had to endure annual tests to check the state of her liver and has also had to endure constant worry of it turning cancerous.
2. Physically, my mum has chronic fatigue, she is always tired, and she has constant itchy skin and would scratch herself until the point of bleeding.
3. When my mum was told she had cirrhosis the treatment that was offered to her was interferon. She was told she needed to have 6 months of the treatment, but because of funding issues she was only given 3 months initially. She then changed doctors and had to fight to get the further 3 months of treatment. This was a very stressful period for my mum, as no other medication was offered to her other than the interferon. Eventually, she received the further 3 months of interferon treatment. After this she had to then go for regular scans and bloods tests, finally she found out that the treatment had been successful and that the Hepatitis C was dormant, but she still has cirrhosis.
4. The mental effects from the treatments that my mum had included her always worrying about whether the treatment was going to be successful, was she going to have a limited life expectancy, what the future actually held and what the impact of her condition was going to have on the rest of the family.
5. Physical effects of the treatments included my mum's hair started to thin, she had shortness of breath and palpitations, her tiredness became worse and worse. My mum also has severe joint pains, crippling arthritis in her hands, weak joints and significant heart problems which may have been induced from the horrendous stress of living with this disease. She had to have an

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emergency pacemaker fitted on the GRO-B and I think the stress of having to relive all this process through this Inquiry has exacerbated her recent heart problems.

6. With regards to how my mum's infection status impacted upon her other medical and dental care, she has always been embarrassed when going to the dentist or doctors or hospital appointments. When she would tell the various individuals about her infection, they would react with shock and unconcealed disgust.
7. My mum has told me that her medical and dental files would have a visible red sticker on them to warn that she had Hepatitis C, which made her feel more ashamed and embarrassed.
8. After my mum found out she had Hepatitis C it hugely impacted her private, family and social life. My mum felt ashamed and embarrassed about the infection and she did not want to talk to anyone about it. She had started a new relationship with someone but once she found out she had Hepatitis C she told him, he subsequently ended the relationship out of fear of catching Hepatitis C and of the future prospects their relationship would have. She was very lonely. She lost a lot of confidence which took her years to rebuild that confidence. Even now she would still suffer from low self esteem and low confidence. Due to this my mum has never tried to find another relationship with anyone, even with my encouragement.
9. My mum did not tell her friends of her infection simply due to the stigma that surrounds Hepatitis C. She did not want to have to experience the feeling of being ashamed and embarrassed all over again while telling them. She also had the worry that they would not want to remain friends or be around her once she told them. Due to this, my mum stopped socialising, isolated herself and stayed at home.
10. Finding out that my mum was infected with Hepatitis C has impacted me in various ways. When my mum received her diagnosis, I was the only family

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member at the time living at home as my sister was at University in GRO-B. My mum suffered from fatigue and became very depressed, due to this I felt I had to stay at home to support her. I didn't want to leave her alone at the time. I was working in a GRO-B and had been given the opportunity to purchase my first home, but I felt I could not pursue this as I did not want to leave my mum. I also didn't want to attend work related training if it was going to involve me being away from home for a period of time. Due to her not wanting to socialise, I wanted to stay at home with her to ensure that she always had someone whom she could talk to.

11. I was always worried when she was receiving her treatment as to whether it would work and whether she would eventually be able to live a normal life. Even now I worry constantly every time she goes for her scans and blood tests, as I fear that if she was to receive bad news, she would not tell me or other family members. It is a heavy weight on my shoulders, as it feels as if mum will never be the happy person she was before she contracted this illness. It has been very difficult and distressing, having to watch someone you love having to go through something like this, while feeling helpless as I cannot do anything but support and be there for her.
12. The impact on my family and I with regards to the stigma of Hepatitis C, is that everyone relates Hepatitis C to substance misuse and promiscuous sex and consequently people can be very judgmental and disapproving. There is also the stigma around cirrhosis, as people relate it to alcohol misuse. My mum has never been a drug user or a drinker and she has never engaged in promiscuous sex either. We constantly have the feeling that if people find out about the Hepatitis C that they will be talking about us and our lifestyle and misjudging a situation that they know nothing about. If my family and/or I have to tell someone about my mum's Hepatitis C or cirrhosis, we feel pressurised to explain the source of the infection and condition. We shouldn't have to do this but we do, to avoid any misconceptions.
13. When my mum found out she had Hepatitis C she was working as a secretary. Due to her having to take so much time off work for hospital

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appointments, she had to tell her employer she had Hepatitis C. I remember the employer was not sympathetic and my mum felt she was isolated. The treatment from the employer and her colleagues was awful, she felt stigmatised and that everyone was talking about her. Due to this she felt she had to leave.

14. She did find other employment but due to her tiredness she could only ever work part time.

15. The financial effects my mum had due to her infection were that she could only work part time. However, in GRO-B she did receive financial payments from Skipton, and she still receives them. These payments have helped, but she only received financial help 9 years after being diagnosed.

16. As I have stated above, I did not want to leave my mum once I found out how serious the infection and cirrhosis was. Due to this I could only remain employed locally as I did not want to travel away to work and leave my mum. I was offered training and job promotion but I turned it down due to my responsibilities at home and because I did not want to leave her alone.

6. Treatment/Care Support

1. My mum has faced significant difficulties in obtaining her treatment. She was told she needed to have 6 months of the treatment interferon, but because of funding issues she was only given 3 months initially. She then changed doctors and had to fight to get the further 3 months of treatment. This was a very stressful period, as no other medication was offered to her other than the interferon. Eventually, she received the further 3 months of interferon treatment. After this she has had to go for regular scans and bloods tests, finally she found out that the treatment had been successful and that the Hepatitis C was dormant, but she still had cirrhosis.

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2. My mum was offered counselling support from the Consultant when she first found out she was infected with the virus, but she was never offered that again even after her treatments. I do not think she was offered any support after this.
3. Due to the lack of support, my mum ended up befriending other people with cirrhosis and Hepatitis C whom she had met from the liver ward in the GRO-B
GRO-B My mum and two of these individuals started the GRO-B
GRO-B The group provided support to each other and led fundraising initiatives to raise money for equipment and to provide assistance to liver patients in GRO-B The group continues to thrive, participation has increased significantly and the group is still in existence today. At the time of our involvement, starting up this group helped my mum meet and befriend other individuals who were in a similar situation to her. It helped her to rebuild her confidence and to become sociable again. To be able to talk to people who understood what she was experiencing emotionally and physically was invaluable to her rehabilitation, especially immediately after surgery and treatment. I attended some of the meetings with her and it also helped me to understand what my mother was experiencing.
4. There was no counselling or psychological support offered to me or any other family members.

7. Financial assistance

1. Mum received financial payments from Skipton but I do not know any further details on this. My mum will provide further details in her witness statement.
2. I have received no financial assistance from the Trusts or Fund set up. I was unaware that any financial assistance was available and I have not been offered any assistance or advice relating to any source of financial assistance.

8. Other Issues

1. I know my mum sought legal advice from [GRO-B] in [GRO-B] however I am unsure what the outcome of this was. I am sure my mum has addressed this in her witness statement.

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Statement of Truth

I believe the facts stated and this witness statement are true.

Signed.....

GRO-B

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Dated.....20103119.....