

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CARYS ELERI REES-JONES

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, Carys Eleri Rees- Jones, will say as follows:-

1. Introduction

1. My name is Carys Eleri Rees – Jones, my date of birth is GRO-C 1979 and my address is known to the Inquiry. I am married and I live with my husband and two children.

2. How Affected

1. My mother was infected via a blood transfusion that she was given shortly after she had a miscarriage in 1982. I was around 12 years old when she was then diagnosed with Hepatitis C in 1991.

2. My mother suffers from severe Von Willebrand's disease. She was given the infected blood product through a transfusion in 1982. She was under the care of Ysbyty Gwynedd at the time. I am unsure whether my mother received any information or advice beforehand.
3. I was only three years old when she was given the transfusion therefore I would not know. I am unsure what information my mother was told. She sat me down when I was 12 and told me that she had it, I felt as if the world was ending.
4. I believe that information of the infection should have been given to my mother sooner. My brothers, my father and I all had to be tested for Hepatitis C when I was around 19.

3. Other infections

1. My mother was not infected with any infection other than Hepatitis C.

4. Consent

1. I am not aware that my mother has ever been treated or tested without her consent, knowledge or without full or adequate information or for the purposes of research.

5. Impact

1. The mental and physical effects of being infected with Hepatitis C have been great for my mother. It really affected her mental health. She tried to commit suicide because she got so severely depressed. When she was in Cardiff for treatment, she tried to jump off a multi-storey car park, she was then admitted to hospital. When she was on the Interferon, she couldn't do anything, she couldn't work, she couldn't be with her children. During the Interferon treatment my mother ended up in Ysbyty Gwynedd.

2. Due to the Hepatitis C she had to have a liver transplant in 2014. I remember seeing her in ITU before the transplant, and she had about three weeks left to live. She wouldn't be here today had she not had the transplant in 2014. She recovered fast after the transplant; she was back working within eight weeks.
3. My mother has been treated with Interferon and Ribavirin, as well as Daclatasvir DCV and Sofosbuvir SOF and the Liver transplant. The only obstacle she faced in receiving treatment is that she had to go down to Cardiff every week for six months to receive the Interferon that was definitely a geographical obstacle for her
4. I believe that my mother should have been given the Daclatasvir DCV and Sofosbuvir SOF and the liver transplant sooner. She was very depressed as a result of the treatment, especially whilst on the Interferon. She wasn't herself at all she was so depressed. My mother's infected status has impacted upon her dental care as she has to go to hospital for any dental treatment.
5. As a result of Hepatitis C, my mother did not have a social life. Because of this it was extremely difficult for the rest of the family as we felt helpless. She felt as if she were a bad mother because she couldn't care for us properly, and when my brother Goronwy was ill she couldn't give him all the care that she wanted to. We missed out on time with our mum because of this.
6. My mother's infected status has also impacted upon me too. I wasn't going out with my friends and so I felt rather secluded from them, and thus I did not have normal friendships because of this. I was the housewife, and I was only 12 years old. When I was a bit older, and she was on the Interferon, I went out working, caring for the elderly during the day, just to come home and care for her during the evenings/nights.
7. It was lucky really that I only lived up the road so I wasn't far if something was urgently wrong. We didn't really have a social family life either, we weren't able

to go on days out, or do any of the things that a "normal" family would do because my mother was so ill most of the time.

8. There is a big stigma surrounding being infected with Hepatitis C, people thought she was a "disgusting, dirty, druggie". You wouldn't dare tell anyone, and we didn't. When my mother was diagnosed, my grandmother was already ill due to infected blood products. That made it harder on my mother as she knew what was ahead of her. I had to look after my brothers when our mother was ill, and I wasn't entitled to carers allowance as I had a job, but that did not lessen the work load.
9. My mother could not go out to work during the time that she was ill, therefore we didn't have much income, and therefore we have struggled financially. I lost a lot of school as I was caring for my mum when she was ill, and when I was looking for work later on, I could only apply for jobs that were close to home in case I needed to rush back and care for my mum if she were to fall ill.

6. Treatment/Care Support

1. My mother can answer better if she faced any obstacles in obtaining treatment, I cannot comment due to my age at the time.
2. I have never been offered psychological support as a result of this, and I'm not entirely sure that my mother has either.

7. Financial Assistance

1. My mother has laid out in her statement the financial assistance that she has received.
2. I have not personally received any payments from any trust/fund. I do believe however that my mother should have been offered more money. I didn't get a carers allowance, so some financial support would have been appreciated, especially when I was still in school and couldn't work myself.

8. Other Issues

1. She should not have received the infected blood in the first place. Why was blood bought from abroad and not tested?

Statement of Truth

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

Signed  GRO-C

Dated 15/3/19