

Witness Name: Jane Ebrillwen Jones

Statement No:WITN2360001

Dated: 28th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JANE EBRILLWEN 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, Jane Ebrillwen Jones, will say as follows:-

1. Introduction

1. My name is Jane Ebrillwen Jones. I live with my partner of 17 years, John Gareth Evans-Hughes. I had 3 children but the eldest has died. I now have a son and a daughter, both have children of their own and live in Pwllheli.

2. How Infected

1. I have mild Von Willebrand's Disease. I was infected with Hepatitis C through cryoprecipitate given to me through transfusion following a large bleed after I miscarried in the first week of August 1982.
2. At the time, I was under the care of Consultant Haematologist Dr Korn at the St David's Hospital in Bangor. I wasn't given any information beforehand

about the risks of being exposed to infected blood. As a result, I was infected with Hepatitis C.

3. I was having stomach pains in the early 1990s, so I went to my local GP which was based in Criccieth, North Wales. He asked to examine me, and whilst he was pressing on my stomach he asked "So, how much alcohol do you consume every week?" I was shocked at this because I don't drink. This was still pressing on my mind a few days later so I phoned Dr Korn and he set up an appointment. I went to see him in clinic and he said I want you to have a scan and a blood test performed for Hepatitis C.
4. I was aware of the condition because GRO-C has it. Dr Korn noted that he didn't expect the results to be anything other than negative. So I didn't give it much thought after that, as I trusted Dr Korn. After having the scan and the blood works done, I went back to clinic on my own. The first thing I noticed when I walked into Dr Korn's office was a yellow sticker on my notes that wasn't there before.
5. He had his head down, and said "I don't know how to tell you this, but the blood test has come back positive for Hepatitis C, and you've contracted this through contaminated blood products". I was there alone that day, as I didn't expect it to be anything other than a negative result. I remember sitting in the foyer of the hospital not knowing what to do with myself. That was the last that was said about it for the next few years really, I just went to clinic regularly for check ups.
6. I wasn't given adequate information about how to manage the Hepatitis C. I should have been given information about Hepatitis C. I was treated very poorly by healthcare professionals, they didn't know anything about Hepatitis C, they were scared to come into contact with me in case they caught it. They left food outside my cubical in the hospital, I would say this happened in around 1993. I practically had to beg them to take me to the bathroom.

7. They wore masks around me and were always gowned up. I believe that they weren't informed of what Hepatitis C was and how a patient who has it should be treated. I was given information about the transmission to others in the early 2000's by Dr Desani at the Haemophilia Centre at the Heath Hospital Cardiff when my partner inquired whether there was a risk of sexual transmission. I started attending the Heath Hospital in the mid 1990s.

3. Other infections

1. Hepatitis C is the only infection I have had from the infected blood products. However I am at high risk of having Creutzfeldt – Jakob Disease.

4. Consent

1. I have never been treated without my knowledge or consent. I have been given adequate and full information for every treatment I have had (except for the initial transfusion). I have been part of a research study, I cannot remember when but I am fairly certain that it was in either Liverpool or Bangor. I recently took part in a trial for the drugs daclatasvir and sofosbuvir in Glan Clwyd Hospital. This treatment was successful.

5. Impact

1. Being infected with Hepatitis C is something you would not wish upon an animal. A few years after the diagnosis, I began feeling extremely ill. I went for a number of scans and blood tests and everything was coming back normal. At that point I had convinced myself that I was imagining being ill, and that I wasn't in fact ill at all because all the doctor's said I was fine. Then there was one day when I went up a ladder at home as we were decorating our bedroom at the time, and I felt so ill I had to lie down in bed for 15 minutes.
2. I went to the hospital, and they finally noticed that something was wrong with my blood and that my stools were black. I was bleeding from the bowel. That was just the start of the illness. After a while I started coughing, again I went

to the doctor and again everything was clear, but I was still extremely ill. Then I remember, it was a Monday morning, John woke me up, and I thought to myself "this is it", I really thought that was going to be the last time I woke up. John took me to hospital, and within an hour I was in ICU at Ysbyty Gwynedd.

3. The severe ascites in my stomach meant that the pressure in my abdomen was so immense that it ruptured a hole in my diaphragm, I was in ICU for 9 days, and they drained 10 litres of fluid from my stomach. This has happened a few times since but I now know the signs so can get it sorted before it goes any worse. My health had deteriorated to the point where I only had one or two months left before I had my liver transplant in 2015. I've had so many incidents in which I have been rushed from Bangor to Liverpool due to severe bleeding.
4. There was one night I went in, and Dr Hamilton in Ysbyty Gwynedd said come back tomorrow morning for more factor 8 but before I even left the ward he had admitted me. That evening I went to the bathroom, assisted by my haemophilia nurse at the time, Nerys. I lost a large amount of blood and was only just able to shout "Nerys" before passing out, I don't remember anything else from that day.
5. When it was initially decided that I was going to have the transplant, I had to two assessments. The first assessment I passed, but before the second assessment I was rushed to ICU in Ysbyty Gwynedd again. When I was in ICU they were debating over sending me to Birmingham for the transplant or not, if they would have sent me that night I would have been too weak to have the transplant, and I wouldn't be here today.
6. The physical effects I have suffered as a result of being infected is cirrhosis of the liver and all of the associated symptoms. I also have a lot of bleeding issues due to the Von Willebrand's Disease.
7. I have been given Interferon, Ribavirin, Daclatasvir and Sofosbuvir as treatments. I have been given Interferon a few times. The first time I was on

Interferon and Ribavirin for 6 months, I was clear of HCV for a while but then it came back almost instantly. Due to the enlarged liver, I had an excessive amount of fluid in the abdomen, which eventually ruptured a hole in my diaphragm which leads to complex surgery to repair it. I have also had a Liver Transplant as a result of the cirrhosis due to the HCV.

8. I have not faced any difficulties in accessing treatment. I have never been aware of any treatments that I consider should have been made available to me. I've received various treatments about 5 times overall so it's never been a problem accessing treatment.

9. The mental effects of the treatment I have received for HCV have been great. I cannot tolerate Interferon, which has been a big problem over the years. The first time I was on a combination of Interferon and Ribavirin, I was on the sofa under a mountain of blankets, shivering, I was so ill I could not eat or drink therefore I lost a considerable amount of weight.

10. At one point I weighed only six stone, and I vividly remember having to hold my trousers up whilst walking in town as they would have fallen down otherwise. The second time I took the Interferon and Ribavirin I had suicidal thoughts, I was also very ill this time too and it was worse as I had the three children to look after and I felt as if I was failing as a mother because they had to look after me, and at the end of the day, they were still kids. The third time I was on Interferon and Ribavirin it destroyed my white blood cells, they were at 0, and I lost all my hair. I also couldn't eat or drink again. It was very challenging as it involved me having to travel down to Cardiff every Monday for 6 months, initially I had to drive myself, but was so ill it was a struggle. Then when I met John he started driving me down, but again I was sometimes too ill to be able to travel four hours in the car driving back and forth so we had to stay the night. The latest treatment I have received was the Daclatasvir and Sofosbuvir, I had no side effects whatsoever with this.

11. My infected status has impacted upon the medical treatment that I have received. I once had to go into hospital to have my gall bladder removed in

the early 90's, and the staff were awful, they refused to come into the cubicle, they left my meals outside, and would refuse to help me to the toilet in case they "caught" HCV. In the end I had insisted to speak with Dr Korn, and he moved me from General Surgical to Alaw Ward (haematology) so that I could be treated by those who would understand more of the condition. I cannot go to the regular dentist with the rest of my family, I have to go to Bryn y Neuadd in Llanfairfechan, other dentists wouldn't take the risk.

12. I don't and didn't have a social life really between the illness and the children.

It bothers me greatly, that there was a period where I couldn't do things with the kids, go for a walk, go to the park, or go and have a picnic on the beach because I was so ill. They were losing out because of that, and I couldn't work due to the illness so the money wasn't there either. Then of course there was a time where I was ill, **GRO-C** and my son was ill. Goronwy (my deceased son) was in Broadgreen Hospital when **GRO-** was rushed to the Royal in Liverpool, and I had to run back and forth between both hospitals whilst still being ill myself. It nearly killed me, but it would have killed me more to sit back and do nothing at all. It has also affected my partner John greatly, a lot of the time when I am extremely ill, I am heavily sedated and sometime unconscious therefore I have no recollection of most of those experiences, unlike John who has had to see it all.

13. There is a big stigma associated with a diagnosis of HCV, mainly due to people's lack of knowledge. Not just lay people but the professionals as well (as mentioned previously in the incident when I had my gall bladder removed) I was congratulated by one of John's friends for being pregnant when I had the severe ascites, and after I corrected him and said that I was there for a liver scan, he said "Gosh, who would have thought, you an alcoholic".

14. Being infected with HCV has not affected my education as I had finished school before I was infected. However the constant bleeding due to the Von Willebrand's was quite disruptive.

15. Being infected with HCV has never adversely affected my work, however I was working in a Hotel as a chambermaid, and I was offered a job at the restaurant downstairs. I asked to think about it for a few days as I did not know if I could handle food with HCV. I didn't know enough myself at that time to explain to my employer so I had to converse with Dr Korn and he confirmed that it was fine as long as I didn't cut myself.
16. When I was going to clinic as an outpatient in around 2013/2014 , just before my Liver Transplant, all the blood tests and scans were coming back clear, so the Doctor's were hiding the full extent away from me. Because they were insisting that all the results were perfectly fine, I started convincing myself that I was imagining it all, and that it was all in my head. Dr Hamilton told me that "I don't think you realise how ill you really are", if the medical staff would have told me the full extent, I would know, how was I to know otherwise? Then because i was convinced that I was imagining it, I pushed myself harder, which ultimately led to further deterioration.
17. The financial burdens of being infected with HCV have been large. During the time that I had to travel down to Cardiff weekly to receive the Interferon, I was on a small wage, and John had to take a day off work each week to take me down to Cardiff so he lost earnings as well. We went down to Cardiff every Monday for 6 months and didn't receive a penny to help. And there were times where I was so ill I had to stay in Cardiff for the night as I couldn't possibly travel. Then there was the time that I had to go to Birmingham to get the liver transplant. Again, the costs of travelling were onerous. We gave up on Cardiff in the end as they noticed how far Cardiff was for us, so I started to be seen in Liverpool instead.
18. My children have been affected mostly by all of this. They had to grow up fast, and they didn't have the chance to be kids, Carys cooked and cleaned and cared for her little brother. Carys had to do more than the boys. Goronwy missed out on his mother being by his side when he was ill himself, I couldn't give him the best care and I do feel guilty about that, I think that hurts more

than anything because now that he's deceased I can't make it up to him either.

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6. Treatment/Care Support

1. I have never faced any difficulties or obstacles in obtaining treatment in consequence of being infected with HCV.
2. I was offered psychological support in Ysbyty Gwynedd, but I never took up the offer. There was nothing they could have done to rectify the situation. I'm not the type of person that talks a lot, I try and cope with things by myself, I get along with things without having to talk to people about it. However I was once admitted for inpatient psychiatric treatment for support after I tried to take my own life in Cardiff during the time I was going back and forth to receive the Interferon. I would say without a doubt that the Interferon was the reason that I tried to kill myself, suicidal thoughts was a side effect of the treatment that I had to grapple with. I believe that this is now a recognized side effect.

7. Financial Assistance

1. I was informed that there was financial assistance available by Ysbyty Gwynedd. About 14 years ago, I received a lump sum from the Skipton Fund. And around 8 years ago, I got another payment when things got worse again. I now receive monthly payments from the Velindre Health Trust.

2. I do not remember having to apply for payments, I received them automatically. I do feel that it is unfair that those infected in Scotland receive more payment than we in the rest of the UK do. It's unjust because at the end of the day, it's the same illness. Why should someone in Scotland that hasn't suffered as much as me, receive less payment than me. At the end of the day, HCV is HCV, and we've all contracted it the same way, so we should receive the same payment across the board.

8. Other Issues

1. The only evidence I have that may be useful to the inquiry is the fact that I keep most of my hospital letters, and one letter notes explicitly "Transfusion Transmitted Hepatitis C". The transfusion that I received has saved my life, but at the same time has turned my life upside down. If someone had given me the option whether to take the infected blood or bleed to death, it isn't really much of a choice is it.
2. I have tried to obtain my medical records. The notes from the first part of the 1980's have disappeared completely. I phoned my Haemophilia Nurse Emma, and she put me in touch with a man called GRO-D when I enquired about my records he got very defensive and cagey questioning why I would want to know as "this has all been sorted out years ago". He then said "you do realise it's going to take time". Emma my nurse phoned back and said that they still cannot locate the missing records, I still hope that I can obtain them.

Statement of Truth

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

Signed... **GRO-C**

Dated... 28-02-2019