

07 FEB 2019

Witness Name: Jane Unwin
Statement No.: WITN0204001
Dated: 31/01/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JANE UNWIN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10th January 2019.

I, Jane Unwin, will say as follows: -

Section 1. Introduction

1. My name is name is Jane Unwin. My date of birth is GRO-C 1954 and my address is known to the Inquiry. I am a retired receptionist and mother of 2, and I intend to speak about my infection with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on mine and my family's lives.

Section 2. How Infected

2. I was infected in August 1991 after spending 10 days on a cell separating machine at the University College Hospital (UCH) in London.
3. I was admitted to Northampton Hospital with a condition called Thrombotic Thrombocytopenic Purpura (TTP). I was coming out in bruises that would

not go away. I was falling asleep a lot which turned out to be me drifting in and out of a coma. I had almost no platelets, so I was just bleeding to death internally which is why there were bruises. They did not know what caused it, but they think it was a virus.

4. I needed to have a transfusion through a cell separating machine. Northampton had the correct machine but no one to operate it, so I was sent to UCH.
5. I arrived on a Thursday and they put me on drips. On Friday I was started on the cell separation machine. I had a needle in both arms. One takes blood out of you. This is then separated into all the different parts that make up your blood. Fresh Frozen Plasma (FFP) is then added before the blood is warmed up and put back into my body through the other needle. The FFP is what infected me.
6. I had no idea that there was a chance I could get infected. I was not warned of any risks, and it was not until the panorama that I knew about infected blood.
7. I was in hospital for 2 weeks. After 10 days on the cell separating machine I was taken off so they could see if my platelets were up again and on the 14th day I was sent home.
8. I returned to Northampton to see Dr Shepherd who I was under before being sent to London. I was having my blood tested every week at the time to keep an eye on my platelet levels. It was between 4 and 5 weeks after the transfusion, in September, that he found the HCV. He was so fast on it.
9. It was not clear to me that the infection had come from my transfusion in London. I knew I was infected with HCV and then when it was on the television I thought 'oh my God' I bet that is how I got it. I had not been anywhere else that I could have been infected.

10. I thought I was being tested just for my platelet levels, but then the doctor told me of my infection and referred me to a liver specialist called Dr **GRO-D**. The doctor was kind about it, but I'm not sure I would describe it as empathetic.
11. Dr **GRO-D** said we were not going to do anything. He said we were going to leave it 6 months as HCV can clear up on its own. Dr Shepherd wanted me to be in the operating room for a liver biopsy right away!
12. I was not given any information about the infection. Nothing on how to live with it, or what to do and what not to do. There was nothing on transferring it either.
13. The following May, in 1991, I had a liver biopsy and it came back as chronic HCV. The doctor looked at my then husband and said we better check him. That was the first time we knew that Gerald could have got it.

Section 3. Other Infections

14. To the best of my knowledge I was only infected with HCV.

Section 4. Consent

15. When I was told of my infection, I had thought they were only testing my blood for my platelet levels. I was not aware they would be testing for HCV.
16. As far as I am aware, I was not treated or tested for purposes of research.

Section 5. Impact

17. After the transfusion I felt a little funny; I put this down to being after effects of the illness. I was diagnosed so quickly there was not much time for me to feel the effects of the HCV.

18. As the HCV was chronic I had to go on Interferon injections. I had to pay for them myself. The course was 6 months long and I took them every other day – so 3 times a week throughout that period. I asked the doctor if there would be any side effects. He told me that there might be flu like symptoms. I asked if I would be able to go to work; he said yes. I was working as a receptionist at the time and there is no way I could have gone to work.
19. The physical effects of the Interferon were wide and long-lasting. You cannot describe it, I just slept and slept for 4 years. It did feel like flu because you are shaking and exhausted but it was much worse than the flu like symptoms we were warned of.
20. Around Christmas they made me redundant from my job. From then I was not able to work again.
21. After the 6-month course I had to wait a further 6 months to see if it had worked. Dr. GRO-D explained that you 'zap' the HCV and leave it to see what has happened. It had not worked, it just was not getting better and it was still chronic.
22. I was told that I would have to go back on a double dosage of Interferon for double the length of time, this time 12 months. The doctor told me I had a choice and that I didn't have to take it. But I did not have a choice, if I didn't take it I would die. I had to give myself the chance.
23. The second round of Interferon was just as bad, it felt like it was never ending. My GP kept telling me that I needed to get a job. I could not wake up, let alone get a job.
24. After this course my blood was being tested regularly, probably once a month. Around 12 months later I got the all clear. I was cleared from HCV by 1995.
25. During the 18 months of Interferon, I had really severe pain in my joints. There were times where I had to carry my own wrists because the pain was

so bad. My knees were really painful too. The doctor just said it was side effects.

26. My knees kept giving out and so did my fingers, so I went to the doctor. I had x-rays taken and they told me I have arthritis. All this pain began 27 years ago, so I am sure it is all connected. I am ok in myself, but I cannot walk very far and I have to use my stick.
27. The drugs caused me to develop thyroid issues too – I have an underactive or hypo-active thyroid. I was put on Thyroxine tablets and my dosage has gone up from 100 to 125 mcg/day. It makes me very tired.
28. I also developed type 1 diabetes in my mid 40's. Again, this must be a side effect from the medication as the doctor said I was quite old to be getting it.
29. In the 1990's there was a film made about these Irish ladies going through the same experience with Interferon and HCV. My friend phoned me after and was so shocked that she had no idea what I was going through.
30. My mental health suffered but because I was so drugged up I couldn't cope with it at the time. I think that is why it is all hitting me now with the Inquiry coming out, because I can engage with it now.
31. Socially, I did not have a life for 4 years. I tried to go out one Saturday night and I nearly passed out. I felt a lot of panic as well. In my house I felt safe and as soon as I stepped outside I was worried about what could happen.
32. At the time I looked after my parents who were in their 70s. I had to go out and try and see them because they needed me. On the 2 days of the week that I didn't take my injections I would go to their house and taken them shopping.
33. My whole family were affected by it. My son and daughter were 12 and 14 and no one told them anything, they just knew that I could die. When my

son was 15 he got in with the wrong crowd. [GRO-C] at the time
I was on Interferon and his father worked nights. [GRO-C]
[GRO-C]

34. For 4 years I missed out on their teenage years. My son now explains that he was so lonely at the time. I was asleep in bed all the time and his father was at work all night and in bed all day.
35. I tried to manage and time my injections to be in the afternoon because I knew that the children would be home, I could have done their teas and have them inside before I had to go to bed. I learnt to manage.
36. I was never accused of being a drug addict or an alcoholic but that is probably because they picked it up so quickly. However, we didn't tell anyone until it was announced on the television because of the stigma.
37. There was a huge stigma associated with HIV/AIDS but Hepatitis C had the same. Once time I was due to have a camera down my throat for something in hospital but I was sent home because I had had a blood transfusion and HCV. My immediate family knew about my infection, but no one else did because you just couldn't talk about it.

Section 6. Treatment/Care/Support

38. I had to pay for my Interferon medication, but I had to take it to give myself a chance of living.
39. I was never offered any counselling or psychological support. With hindsight in particular, I would have liked access to something. They had said I would be able to go to work as I would just get flu symptoms, but this was far from my experience.
40. It broke my marriage. My then husband would have left me during the time I was on Interferon if it weren't for the stigma he would have experienced for

doing so. We were just going along blindly. If someone had said this is going to be really tough on all of you then maybe we both would have coped better.

41. I felt alone throughout the whole experience. Not lonely necessarily, but alone. There was only Dr [GRO-D] that I could really talk to, but of course doctors are so busy with their clinics that I could not take up his whole time.

42. I have been made aware of the support being offered by the Inquiry and the Red Cross.

Section 7. Financial Assistance

43. No support was ever made available to me until November 2016 when I received a letter from the Skipton Fund stating that they would be sending me £3,500 by December 2016. This was the first I had heard about any financial support being available.

44. I had stopped working again in March 2018 and so I am grateful that these payments do not affect my benefits claims. The supplier has now changed from Skipton to EIBSS.

45. In April 2017, I was then informed I would be receiving £15,665 annually but this changed again in 2018 to be £18,599 per year. In December I get £519 fuel allowance too.

Statement of Truth

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

Signed

[GRO-C]

Dated: 5/2/2019