

Witness Name: Nerys Humphries

Statement No: WITN3170001

Dated: 24th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NERYS HUMPHRIES

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 14th May 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Nerys Humphries, will say as follows: -

1. Introduction

1. My name is Nerys Humphries. My date of birth is GRO-C 1959 and my address is known to the Inquiry. I intend to discuss the impact on myself and my family as a result of my husband, Mark Humphries, contracting hepatitis C from contaminated blood transfusions/products during his treatment for leukaemia in 1985-86. However my husband believes that it is more likely he contracted hepatitis C as a result of a blood transfusion in approximately 1987-89 at the University College Hospital in London (UCL).

2. By way of background, I live at my current address with my husband; our son is currently at University. I am employed and my husband is semi-retired.
3. I met Mark when we both worked at the National Museum of Wales in Cardiff in 1992. We married in 1994 and I had our son in GRO-C 1996. It was during my pregnancy that we found out that Mark had contracted hepatitis C.

2. How Infected

1. I knew that my husband had received a great deal of treatment for his leukaemia in 1985-86 and 1987-89 and that he was treated at the University Hospital (UHW) in Cardiff and the University College Hospital in London (UCL). Part of his treatment included blood based products including full transfusions. I was also aware that it had taken some time for him to recover and get back to full health.
2. As a result of these blood transfusion/blood based products he contracted hepatitis C.

3. Other infections

1. I am not aware that he had any other infections other than hepatitis C, although he had his gallbladder removed before hepatitis C was diagnosed as the medics believed that might have been the cause of his "feeling unwell".

4. Consent

1. I do not have any knowledge as to whether he was treated or tested without his knowledge, or consent without being given adequate or full information or for research.

5. Impact

1. It was towards the latter stages of my pregnancy in 1996 when Mark was watching a Panorama documentary on contaminated blood and how many patients were unaware that they may have contracted hepatitis C. I can recall him saying "I think that's me". I was in the house at the time but can't recall sitting down and watching the programme, although I may have dipped in and out of the room whilst it was on.
2. A few days later Mark made an appointment to see our local GP and asked to be tested for hepatitis C and a couple of weeks later the results came back as positive. I can recall that Mark had previously told me that he had a lot of reactions to blood transfusions. My initial reaction was that this was unlikely.
3. When Mark's test proved positive, it was a total shock. I was still pregnant at the time and we were both extremely worried and concerned not only that I had contracted hepatitis C through unprotected sex but was there a risk to our unborn child.
4. I was tested before he was born and thankfully the results came back clear. We wanted our son to be tested whilst in the womb but the medical profession strongly advised against this as it was fraught with risk and complications. They also told us that as I was clear of the virus the risk to the unborn child was extremely low or non-existent, even if I had the virus the transfer through the placenta was unlikely. Even though we were told this I still had an element of doubt as if they could infect Mark with a hepatitis C then we were worried that it could happen again. Our son was born in GRO-C 1996 GRO-C

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5. I remember that Mark was quite adamant that he thought he also had contracted hepatitis C from his time in London.
6. Mark's treatment for hepatitis C started in 1996 and continued up until 2016 when he was given the all clear.
7. Between 1996 and 2001 Mark had four courses of treatment. It was difficult to see Mark going through these debilitating treatments. Helping him with Interferon injections was distressing, especially when they caused swelling. I saw first-hand how tired he became, suffering from dizziness, headaches and general weakness. He often had trouble sleeping and felt either cold or feverish.
8. During this 20 year period Mark endured so many setbacks in the various treatments being administered. There were gaps of sometimes several years in his treatment as he had a negative response or allergic reaction and treatment was stopped as there was no benefit in continuing. It wasn't until April 2016, when he was given Harvoni and Ribavirin that provided a positive sustained virologic response with no ongoing infection from hepatitis C virus.
9. Life with a young baby was very demanding but the addition of hepatitis C made our early family life very stressful. There was the unknown factor of what the long-term prognosis might be and wondering if I would lose my husband and our son his father. Mark, during treatment periods in the first five years, was unable to play with our son because he was feeling so awful.
10. Prior to Mark being diagnosed with hepatitis C we always wanted more children but with Mark being so ill and with the treatment not working this hope faded as we saw it as an unnecessary risk.
11. Over the years Mark's hepatitis has become part of our family life and it was not until our son had gone to university that Mark became clear of the illness. It seems so unfair that having beaten leukaemia he was

infected by blood products that should have been saving his life. It is upsetting to realise that hospitals and the blood transfusion services were aware of problems for a long time and that the government has only now allowed an Inquiry into this scandal. The problem has affected more than just the people who received the infected blood products. Our family life could have been very different; and our son could have had a brother or sister. Mark would have had more energy to play with our son and we would not have had to worry about what would happen if Mark developed cirrhosis of the liver.

12. We love going on holidays and have travelled extensively all over the world but even this was stressful as we either didn't go or took a risk of going without travel insurance as the costs were astronomical. Most of the time we took a risk travelling without insurance and although we thoroughly enjoyed our times away there was always that nagging doubt hanging over us whether he would be taken ill whilst abroad and how we would cope with that. There was also the added stigma of having to take "sharps" on holidays with us for the Interferon treatment and worried about what the hotel cleaning staff thought when finding these in our room.

13. Although Mark has been given the all clear he still gets very tired, suffers with severe stomach and IBS type symptoms which I believe is directly linked to the removal of his gall bladder and the early treatment he was receiving more specifically with Interferon. This limits what he can eat and he needs to be close to a toilet as he sometimes needs to use it at very short notice.

14. My husband made a poignant comment in his statement where he states that "our lives have been framed around him contracting hepatitis C" and everything we did and to some extent still does revolve around this horrendous condition and its after effects.

6. Treatment/Care Support

1. The treatment included Interferon Monotherapy, Interferon and Ribavirin, Interferon, ribavirin and amantadine and also Pegylated Interferon and Ribavirin.
2. As Mark found it difficult to administer some of the drugs I was taught how to do so. It wasn't easy for me to do and it was painful for him.
3. Mark's liver has been damaged and was diagnosed with fibrosis, but I am unsure of the date of the diagnosis.
4. No one sat down with us and identified the problems other than comments about only having protected sex and not using each other's toothbrushes

7. Financial Assistance

1. Mark has received was £20,000 from the Skipton Fund in 1997. However, following a successful application in the last six months he has been receiving payments from EIBSS under the SCM scheme.

8. Other Issues

1. It upset me when Mark applied for his medical records from the University College Hospital, London as it contained a number of negative and false comments about his dad, John Humphries. Marks' dad was a well-respected member of society, he was the editor of Wales largest newspaper, the Western Mail, and he had been invited to 10 Downing Street to meet with Tony Blair as he had raised over £1m for a donor match charity. The notes implied that "he was aggressive" and the general tone was not pleasant for someone I have great respect for.
2. I am really annoyed and frustrated by the injustice of how long we have had to wait for answers as to why Mark was infected. As a family we

deserve to know what happened and deserve justice for what he has been put through.

Statement of Truth

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

Signed...

GRO-C

Dated...

23/4/19