Witness Name: Maureen Hayes
Statement No.: WITN3412001
Exhibits: WITN3412002 -
WITN3412008
Dated: 19. 10. 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MAUREEN HAYES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 June 2019.

I, Maureen Hayes, will say as follows: -

Section 1. Introduction

1. My name is Maureen Hayes. My date of birth is GRO-C 1946 and my address is known to the Inquiry. I am retired now, but prior to my retirement I was a community support worker for Cheshire Social Services.

2. I live with my husband who is GRO-C. We have 3 children aged 51, 49 and 34. They are always around to help if needed.

3. I was infected with Hepatitis C through the administration of a blood product namely, Immunoglobulin in 1984. In my statement below, I intend to speak about the nature of my illness, how the illness affected me, the treatment received and the impact it has had, not only on my life, but that of my family too.

Section 2. How Infected

4. On 30 June 1984 when I was 16 weeks pregnant with my daughter I developed a rash and went to see my local GP, Dr Rose. Dr Rose took a blood sample as he suspected I may have contracted rubella, a very serious illness if contracted during pregnancy. He sent the blood samples off to Withington Hospital. As a precaution in case the blood test came back positive for rubella, he gave me an Anti-D Immunoglobulin injection (a blood product). I later learned that this was how I was infected with the Hepatitis C virus.

5. The blood test results that Dr Rose sent away came back negative for Rubella. He then referred me to Dr Felmingham, who undertook more tests. A third blood sample, taken on 11 July 1984, did test positive for Rubella (WITN3412002).

6. My daughter was born perfectly normal on GRO-C 1984 which was a huge relief as I was concerned that she could have been affected by the rubella I suffered during my pregnancy. I was particularly concerned about her being born blind or with a mental handicap which is a possible consequence of contracting Rubella during pregnancy.

7. I was not informed of any potential risk of receiving contaminated blood as a consequence of the Anti-D Immunoglobulin injection.

Section 3. Other Infections

8. I do not believe that as a result of being given contaminated blood products I have been infected with anything other than HCV. That being said, as a consequence of the HCV infection, I have developed liver cancer.

Section 4. Consent

9. I do not believe nor am I aware of ever being tested or receiving any treatment without my consent.

10. I think it was in about 2010 when the Hep C Clinic at the Queen Elizabeth in Birmingham asked me to give blood every year as part of a research project which I did.

Section 5. Impact

11. For many years I suffered from constant fatigue, weakness, muscle and joint pain and a general feeling of illness. There were times when I honestly don't know how I got out of bed in the morning. This obviously had a profound effect on our family life although I tried my best to make each day as normal as possible.

12. As a consequence of my illness and fatigue, there were times when I was unable to do some of the activities that I had previously enjoyed. This had a severe impact on our family and social life as I felt unable to attend events or go on outings with my family and friends. This obviously affected my husband Ken as there were times when I was simply too tired to go out with him.

13. Life's simple pleasures such as going for a walk or gardening, which I had always enjoyed became impossible for me. It was just too difficult - I just didn't have the energy for them. I had always grown all my own vegetables and at one time even had a greenhouse, but I had to give it all up because of the HCV infection.

14. At the age of 62 I decided to take early retirement as I felt I could no longer work. I was unwell and constantly exhausted. As a rural community support worker my job was both physically and mentally draining. My core work involved assisting elderly people in their homes,

many of whom suffered from dementia. I found my job very rewarding and despite not having worked for 10 years now, I still miss it very much.

15. Taking early retirement meant that my income was reduced by almost £1,000 per month. This reduction in income hit us very hard financially. I had only ever worked on a part-time basis so do not get a good pension. I receive only £300 from my government pension and an additional £150 from the Cheshire County Council. If it were not for my husband's pension, we would have really struggled to make ends meet.

16. I am aware that the financial strain coupled with the strain and worry of being so ill, made me difficult to live with at times. Generally, however, I do have a very good, positive outlook on life and don't let much get me down.

17. When I was first diagnosed with HCV I felt quite ashamed of my condition but in time I got over the feeling of shame and accepted my illness. My husband Ken has found it less easy to accept however.

18. Although I have been told not to worry, I live with a constant fear that my daughter has also been infected with the Hepatitis C virus, because of the fact that I was pregnant with her at the time that I received the infected blood product. She has never been tested.

19. I have cirrhosis of the liver and was diagnosed with liver cancer in 2018. I am receiving treatment for liver cancer but the outlook is uncertain. Although, I was until recently on the list for a liver transplant, I have now been removed from this list as the doctors are concerned that my lungs are not strong enough to cope with such an enormous operation. I have asked for a review of this decision as I feel that a liver transplant would be the best course of action to take despite the risks, which I am fully aware of.

20. Despite the damage to my liver caused by the HCV infection and now the liver cancer, I feel more healthy and energetic than I have for years and am prepared to do whatever will give me more years with my husband, children and grandchildren.

Section 6. Treatment/Care/Support

21. Towards the end of 2003 I went to see my family doctor, Dr Rossall as I was feeling constantly ill and extremely tired who referred me to Dr McKay, a physician at the Victoria Infirmary in Northwich. On investigation it was established that I had contracted the hepatitis C virus. (WITN3412003). Dr McKay discussed the treatment of hepatitis C with me.

22. Initially I was diagnosed as suffering from auto-immune hepatitis. I was treated with Azathioprine but did not respond as the doctors had hoped. After a period of 9 months on this course of treatment, more tests revealed that I was instead infected with the hepatitis C Genotype 4 virus which is of Arabic origin and is quite rare I was told. I have never met or been in contact with anyone of Arabic origin and can only have been infected by this genotype through the blood transfusion I received.

23. Dr Youssuf, who had genotyped the virus, explained my HCV infection clearly to me and assured me there was minimal risk to my family and others around me, provided I took the necessary safety measures at work, such as wearing gloves.

24. Early in 2005, I was prescribed a 12-week course of pegylated Interferon combined with Ribavirin but this also did not have the desired effect. This treatment was administered through an injection into my stomach as well as tablets. I suffered some severe side effects with this treatment - my arm swelled really badly, I was breathless and very tired all the time. I recall on one occasion after having my injection, I started shaking so

badly that I had to put a flannel between my teeth. It did not get rid of the hepatitis C virus.

25. In April 2005 my Consultant Physician, Dr Mutimer at the Queen Elizabeth Hospital Liver Clinic where I had then been referred, confirmed after a liver biopsy, that I had developed cirrhosis of the liver due to the HCV infection.

26. In 2008/2009, I was put on a 10-week course of an American treatment. Again, I suffered horrendous side effects. My lips swelled to such an extent that they would spontaneously start bleeding – basically they burst open. The skin on my face peeled so badly that at one stage the doctors thought that I may have to have plastic surgery to repair the damage caused by the treatment. I haven't had to fortunately, it did repair on its own once I had stopped taking the medication. It was extremely painful and embarrassing to have my face so disfigured by a course of medical treatment. To make matters even worse, the course of treatment was unsuccessful.

27. In 2015, I was told that a new, breakthrough treatment was available which worked. Despite suffering from such awful side effects during my two previous HCV treatments, I decided to have the treatment. I underwent a 12-month course of Sofosbuvir (Sovaldi) Ledipasvir and the HCV was successfully eradicated from my body (WITN3412004). Fortunately, I suffered minimal side effects on this treatment.

28. After being cured of hepatitis C, my energy levels increased again and I no longer feel constantly tired. I do still suffer from very dry skin and bruise easily. Despite 6-monthly dental check-ups, my teeth are not good, they crumble which I believe is as a consequence of the medication I have received over the years.

29. The treatment that I have received over the years from the NHS has been very good; I cannot fault it. I was particularly well supported by my

allocated nurse, Katrina. I remember her saying to me on one occasion "You are very ill Maureen and high on our watch list". Her words reminded me that I was really quite ill, as I did not quite realise how sick I really was.

Section 7. Financial Assistance

30. In 2006, I applied to the Skipton Fund for financial assistance (WITN3412005). My claim was rejected on the basis that I had not provided them with enough information.

31. With the assistance of Dr McKay, I reapplied to the Skipton Fund in 2007. Once again, my claim was rejected, this time on the basis that there was a lack of supporting confirmation that I had been infected with HCV through NHS blood or blood products prior to September 1991. They said that they had been informed by The National Blood Service that the Immunoglobulin blood product that I had been given in 1984 was safe and therefore not a possible route of hepatitis C infection (WITN3412006).

32. I was invited to appeal against the decision which I promptly did. I explained in my appeal letter that the only blood or blood product I have ever received was the Immunoglobulin and that I have always led a clean lifestyle. The only possible source of my HCV infection is through this blood product. (WITN3412007)

33. The Skipton Fund Appeal Panel accepted that the only blood product I had ever received was the Anti-D Immunoglobulin in 1984. They said that only British NHS anti-D would have been used and that there had been no evidence that this product carried any risk of transmitting HCV. They added that imported anti-D products were known to have carried such risks at the time but would not have been used in my case (WITN3412008).

34. After my appeal had once again been rejected, I wrote to the Fund for the return of my file of documents which I had submitted to them in support of my claim. I never received all my documents back from them.

35. Had I been successful in my claim, I would have been entitled to receive a lump sum payment of £45,000 from the Fund. This would have been enormously helpful given my reduced income. I believe that the decision of the Fund is incorrect and that I should be entitled to the financial support offered to people infected with hepatitis C through contaminated blood products.

Statement of Truth

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

Signed GRO-C

Dated 19. 10. 2019.