

Witness Name: Marlene Dobey
Statement No.: WITN3325001
Exhibits: WITN3325002 – WITN3325007
Dated: 21 January 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARLENE DOBEY

Section 1. Introduction

1. My name is Marlene Dobey. My date of birth is GRO-C 1954 and my address is known to the Inquiry.
2. I live in GRO-C and have two adult sons.

Section 2. How Infected

3. On GRO-C 1973 I gave birth to my son at Ashington General Hospital at 7:45am. Shortly after he was born, I was asked if I was going to have any more babies. I was 19 years old at the time, and I said of course I intended to have more children in the future. The midwife told me that I would need to have an injection called 'Anti-D' to prevent any complications in future pregnancies which can occur because my blood group is Rhesus A Negative.

4. The midwife then went on to explain briefly the complications which can arise because of having Rhesus A negative blood, including the risk of having babies with birth defects, and of still births and miscarriages. She did not say there were any risks involved in having an Anti-D injection.

5. I agreed to have the injection, and it was administered later on the day after my son was born. **WITN3325002.**
6. For a little while after the birth I did have the odd day of not feeling 100%, and I put it down to being a new mum for the first time and naturally being tired and on some days a bit nauseous. I did have a hiatus hernia during my pregnancy and I just assumed the queasiness was from that and never thought any more about it.
7. About two years after my son was born, I was invited by the blood transfusion service to come in to become a blood donor as my blood group is not too common. I was told it would be beneficial to donate blood and could assist patients in the process of having kidney transplants. I didn't hesitate to sign up as I was more than happy to help.
8. After I had donated about 7 pints of blood, I received a letter saying that my blood was not suitable for donation because "there was something wrong with it." Those were the words they used. They gave no explanation as to what was wrong with it and no indication that I needed further testing or medical care. I was just told that I was no longer eligible to be a donor.
9. Not long after that I became pregnant with my second child. I regularly attended my ante-natal checkups at the GP and the local ante-natal clinic. Towards the end of my pregnancy there was a problem with one of my tests and it was mentioned that my baby may require a blood transfusion while still being in the womb. The reason was given that I had started to produce some antibodies which could potentially harm the baby.

10. The transfusion thankfully did not take place as the problem somehow resolved itself and my son was born about two to three weeks after his due date. The birth was induced and when he was born, he was quite jaundiced and had to be placed in the neonatal unit for about 4 to 5 days. The staff assured me that babies can develop jaundice if they are well over due.

11. I think it was within the first or second year after my second son was born that I became unwell with jaundice and pains in my right side of my abdomen. My GP said it was some sort of infection more than likely from my kidneys, as I had often had kidney infections in the past.
12. Since that jaundice episode, I have often had some discomfort, aches and pains in that same area, but whenever I have had investigations nothing abnormal or remarkable was found apart from a fatty liver and possible gall stones.
13. In 2002, when I was living in Kent, I had an allergic reaction to nicotine patches. I was trying to give up cigarettes at the time and I went to the William Harvey Hospital as I was in a very poorly state with rapid heart beats and very high blood pressure.
14. After my discharge from the hospital I went to the GP for some follow up blood tests. She was a locum GP from South America. She told me that I have hepatitis C (HCV). She said that HCV can be transmitted via sexual contact or transfusions and asked if I had had multiple partners or been given blood. When I said no to her questions, she said that it was blood borne and that I could only have been infected from blood. At that point she said she was going to pass me over to her colleague as he was a permanent member of staff.
15. I was in total shock and extremely upset, especially when she asked if I had ever injected drugs or had multiple sexual partners. I was stunned. I told her there is no way I could have been infected as I have never ever been a drug addict and I am certainly not promiscuous, as I met my husband when I was 14

and we married when I was 18, and I most certainly have not had extra marital affairs.

16. I was then passed to the permanent GP, who did more tests and said that the results indicated that no further treatment was needed. He did not say anything about how the virus could progress or what treatment I might need in future.
17. In 2008, the HCV was mentioned again when I had medical tests done by Dr Perros at the Royal Victoria Hospital in Newcastle. I was under investigations for the usual abdominal discomfort when I was sent for a CT scan which revealed an Adenoma on my adrenal gland. Dr Perros had my blood screened for various antibodies and it was discovered that I had HCV antibodies again. Just like the GP in Kent, Dr Perros asked the same questions about my risk factors for contracting the virus and I gave him the same answers. He decided to refer me to the Freeman Hospital in Newcastle under the gastroenterology department.
18. Dr Hudson at the Freeman Hospital did some further tests and discovered that somehow my body had cleared the virus and the virus was not active (I was PCR negative). **WITN3325003**. However, he noted that that did not mean I am immune to re-infection with hepatitis and I could still be at risk of having problems in later years. He said I had no risk factors for HCV **WITN3325004**. He also that in about 15% of cases some people clear the virus naturally within a short time, but that most people need prompt treatment to try to clear the HCV.
19. I am certain that the virus was originally given to me via the Anti-D injection that I received after having my first son, as after doing my own research I have discovered that some infected blood was given to the UK from America and some of it was used to make blood products like Anti D. Anti D is made from human blood plasma.

20. I believe that I should have been referred to see Dr Hudson in 2002 after being diagnosed. I do not understand why my GP said that no further tests or monitoring was needed. If I had cleared the virus naturally by that point, I would have been relieved of some of the serious anxiety and distress I suffered due to knowing I had HCV. If I had not yet cleared the virus I should have been referred to a specialist for treatment.
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21. I also believe I should have been diagnosed earlier, such as when I was told I could no longer donate blood.

Section 3. Other Infections

22. I was infected with HCV only.

Section 4. Consent

23. I was told to have the Anti-D injection just hours after giving birth to my first child. I was only 19 years old and was told I needed to have it if I planned to have any more children. I was not told of any risks of having the Anti-D injection, only that if I didn't have it my future children could be born with severe abnormalities, or be a stillborn or miscarriage. I felt I had no other option so I agreed to have the injection. If I was told about the risk of infection I most certainly would not have agreed.

Section 5. Impact

24. From the time my second son was born I became jaundiced, and experienced pain in the right side of my abdomen. The jaundice resolved some time after that but I have continued to suffer from pains in my side and general aches and pains for many years. I have also had stomach pain, and unexplained chest pain and heart palpitations. I have been told that I have a fatty liver.

25. From 2002, I became anxious about my health and was also anxious that my doctors didn't believe that I was experiencing symptoms because my tests did not show anything wrong. I saw once that my doctor had written 'hypochondriac' in red ink on the front cover of my medical file, because I saw her about pains I was having in my right side around the liver area and my scans showed nothing untoward. That was at the onset of the investigations which led to me being diagnosed with HCV.
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26. Since being told about the HCV I have felt a huge amount of embarrassment and shame about having it. I do think some people still have a stigma regarding HCV. I have not told anyone about my HCV. I have kept quiet from my family and friends. My husband is the only person that knows about it. Since this investigation I have now told my two sons, my brother and my sister, mainly because I thought perhaps my siblings may be infected if the virus came from our parents. I must admit telling them was very daunting and I am pleased to say they have been very understanding.
27. I did not receive any treatment for my HCV. My GP in Kent who diagnosed it in 2002 did not feel I needed to be treated. In 2008, by the time it was diagnosed again in Newcastle it was determined that I had cleared the virus so did not require treatment.
28. Although I have cleared the virus, I am aware that my liver has still been damaged and I may continue to run into problems with it later on as a result of the infection.
29. I do feel I have been treated differently by medical staff as a result of the infection. When I was in hospital having my thyroid removed due to cancer, I overheard staff discussing me during a handover. The nurse told the staff that I was HCV positive and that they had to be aware, but not to treat me differently. Most of the staff were fine, but at times I did feel some reserve from one or two.

30. I feel I should have been offered treatment at the time of my diagnosis. I do not know when I cleared the virus, and would have preferred to have treatment if I had not cleared it shortly after diagnosis, rather than waiting six years to be referred to a specialist for investigations.

31. Throughout my life I have mainly worked as a cleaner. After my diagnosis I initially kept it quiet from my employers. However in 2008 I was applying for a job as a part time cleaner with the NHS and I told the interview panel that I had HCV. They were fine with it, as they said the likelihood of infecting someone would be very slim. My work colleagues do not know about my HCV. Now that I have retired I do not think they need to know.

32. My husband has been 100% behind me all the way. My two sons have been supportive since I told them earlier this year. My younger son is a bit concerned because I was infected before his birth, and he was jaundiced when he was born. He knows that in some cases it can be passed from mother to baby. I have asked him if he would like to be tested. He said he will if the outcome proves that Anti-D is the main cause of my infection.

Section 6. Treatment/Care/Support

33. I believe that counselling should be offered to all who have been infected with HCV. I was not offered that service at the time. Not even when I was diagnosed with cancer and dermatomyositis. The only counselling I have had was recently when my father passed away in 2015.

Section 7. Financial Assistance

34. I applied for financial assistance from EIBSS in late 2018. As part of my application my GP wrote to Dr Hudson and asked him to confirm that the Anti-D was the likely source of my infection, which he did. **WITN3325005**. However, my application was rejected.

35. My rejection letter from 8 April 2019 states **WITN3325006**:

The medical professional who completed your form has indicated that you naturally cleared the hepatitis C virus, without treatment, within the first six months of infection and have only ever tested positive for hepatitis C antibodies. Due to eliminating the virus in its acute stage you are not eligible for EIBSS hepatitis C stage 1 payments.

36. I then appealed that decision in June 2019. I received a letter on 15 July 2019 stating that the decision not to grant me financial assistance had been upheld. The letter states **WITN3325007**:

The Panel noted that your application was based on your belief that you developed Hepatitis C following the administration of Anti-D immunoglobulin in the 1970s. The Panel's view was this was unlikely to be the source of your infection as you would have been provided with intramuscular Ant-D by the NHS at that time which has a very good safety record with no documented reports of hepatitis C being transmitted. By contrast, it was intravenous Anti-D immunoglobulin, which was manufactured in a different way which had previously been associated with the transmission of hepatitis C infection.

With regard to your hepatitis C infection itself, the Panel noted that you appeared to have naturally cleared the infection without any treatment and that this is more likely than not to have occurred within the first 6 months of infection. There was also no evidence provided to suggest that you had developed a chronic infection at any point which is one of the criteria for stage one payments. The Panel were consequently unable to conclude that it was more likely than not that your hepatitis C infection resulted from qualifying NHS treatment or was chronic in nature as required for a payment by the Scheme. Accordingly we regret that we must refuse your appeal.

37. I do not understand why EIBSS has taken the view that I could not have gotten HCV from the Anti-D injection. Anti-D is a product made from pooled blood plasma, and there is evidence of people contracting hepatitis from it. I have no other risk factors, so this must be how I contracted the virus. I have also had doctors tell me that I must have contracted it medically, and I have not had any blood transfusions or other blood products so it can only be from the injection.

38. I also do not understand how EIBSS has come to the conclusion that I must have cleared HCV within 6 months of contracting it. When I was diagnosed in 2002 the doctor told me that I had active hepatitis, so I would have already had it for about 30 years by that time.

39. I am very angry about how I have been treated by EIBSS. In my view they think my case is menial and not relevant because I am not dead or dying, or because I was not infected from a blood transfusion. If I was HIV positive they would help me. I do not understand why they feel a needle stick is more relevant than an intramuscular injection. The virus can still get into the bloodstream from an intramuscular injection. I feel their decision is arbitrary, and that if I had been infected by accidental needle stick injury while being at work the outcome would be different.

Section 8. Other Issues

40. I have decided to make this statement because there may be women like me who are walking around totally unaware that they have been infected, or even who were previously infected and then cleared the virus naturally.

41. If that injection was not the culprit, the infection had to come from one of the medical procedures I had, whether it was due to poorly sterilised equipment and cross infection or human carelessness. In my opinion this virus could not only have infected me, it could have infected and affected my second son, so that is not one life but two lives at risk.

42. The issues I would like to be considered are: how I was infected in the first instance, as I know I did not have a blood transfusion and I do not have any of the other typical risk factors, so it must have been a medical procedure. I also think the Inquiry should consider that not all people who are infected present the exact same symptoms, everyone shows different signs. Some people have

a natural ability to clear the virus and should still be given the opportunity to have treatment and follow up help if required.

43. I hope the Inquiry will make everyone concerned think twice about their actions and how the consequences have affected the infected and their families, and most of all admit they have made a huge mistake and own up to blame.

Statement of Truth

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

Signed

GRO-C

Dated21 January 2020.....