Witness Name: Terence Drane Statement No.: WITN3286001

Exhibits: WITN3286002 - 07

Dated: 22 August 2019

INFECTED BLOOD INQUIRY
WRITTEN STATEMENT OF TERENCE DRANE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 May 2019.

I, Terence Drane, will say as follows: -

## **Section 1. Introduction**

1. My name is Terence Drane. My date of birth is GRO-C 1943 and my address is known to the Inquiry. I am the widower of Maureen Drane (DOB: GRO-C 1946 – DOD: 21.9.2018). I intend to speak about the nature of my late wife's illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

# Section 2. How Affected

2. Maureen was my best friend, she was my world. We married on 22 July 1967. Maureen and I had two children, Lee Drane and Kerri Hudson. Lee is single and currently lives with me, and has done for the last 10 years. Lee was a great help supporting his mother in the day to day running of the house. Kerri is married to Simon Hudson and has two

children, **GRO-C** I have always worked full-time but since retirement at the age of 65 I work part-time as a gardener.

- 3. Maureen had a hysterectomy on 9 August 1994 at the St Margaret's Hospital. The letter from the gynaecological out-patients department dated 21 September 1994 and is addressed to Maureen's GP, Dr D Lowry confirms that Maureen was transfused two units of blood during this surgery. A copy of the letter is attached and labelled WITN3286002.
- 4. The blood which was given to Maureen was of PRB A Negative blood both units expiring on 2 September 1994. The blood numbers were 326787J3 and 326874J8. As a consequence of being transfused with contaminated blood Maureen contracted hepatitis C. A copy of the letter is attached and labelled **WITN3286003**.
- 5. Although Maureen had a subtotal thyroidectomy for goitre in 1990 and the hysterectomy operation in 1994, she was generally in good health and did not suffer from any serious illnesses and was rarely ill.
- 6. Maureen's mother lived into her eighties, and her siblings are also in their eighties and are still alive. Given that Maureen was a very active person who led a healthy lifestyle, I do not doubt that but for the fact that she contracted hepatitis C, she would have lived into her eighties too.
- 7. Maureen was a devoted wife and mother, who worked very hard both in terms of looking after her family and her job.
- 8. Maureen was very dedicated to the Princess Alexandra Hospital where she worked as a nurse auxiliary. We were both surprised when following the diagnosis of hepatitis C the Princess Alexandra Hospital were happy for Maureen to continue working within the maternity ward. However, Maureen did not feel comfortable with this, and in addition she was suffering with chronic exhaustion and fatigue. Soon after she quit her job

- at the Princess Alexandra Hospital. A short period later, Maureen began working as an office administrator at the Epping Forest District Council.
- 9. At the time of the hysterectomy operation, Maureen was under the care of Dr Wilson, Consultant Obstetrician and Gynaecologist from St Margaret's Hospital, Epping. Dr Kamala and Dr Tracey Masters were the surgeons who operated on Maureen.
- 10. Initially all appeared well after the hysterectomy operation and associated blood transfusion. Maureen seemed to be coping well. However, from 15 September 1994 Maureen had become noticeably jaundiced. She also suffered with nausea, vomiting and had diarrhoea. Maureen's urine was also looking very dark. The letter sent to Dr D Lowry dated 21 September 1994 confirms that Maureen had the above symptoms. A copy of the letter is already attached and labelled WITN3286002.
- 11. As far as I can recall the above symptoms continued for approximately four weeks and Maureen underwent a number of blood tests, including hepatitis A, B & C, clotting factors U&E's and LFT'S.
- 12. Further to the tests and investigations a diagnosis of hepatitis A infection was made in October 1994 as evidenced in the letter attached and labelled **WITN3286004**.
- 13. However, in February 1995 according to Dr P.C. Richardson as set out in his letter:
  - "...We now find that she has antibodies to hepatitis C. She has made a complete recovery from her clinical hepatitis which I thought was consistent with hepatitis A but of course, she did have a blood transfusion in August last year. It is not for me to say what patients can get up to on holidays in Malta as hepatitis C can be acquired sexually or via an infected blood transfusion..."

A copy of the letter is attached labelled WITN3286005.

- 14. I remember Maureen being both disgusted and very upset about the fact that clinicians who were involved in her care seemed to be implying that Maureen might have contracted the infection as a result of having had casual sex in Malta. This was categorically not the case. Maureen and I were on holiday together and were very happy. We were both extremely hurt when we read the letter which is attached and labelled WITN3286006.
- 15. After a few years of hospital admissions due to Maureen's hepatitis like illnesses Maureen had a liver biopsy in March 1997. The biopsy showed features consistent with chronic active hepatitis C as a consequence of Maureen's hepatitis C infection.
- 16. However, Maureen was not told that she contracted hepatitis C as a consequence of the blood transfusion until 1998. This is evidenced in the letter sent from Dr Whalley BMed Sci of the University Department of Medicine addressed to Maureen's GP Dr Pradhan:
  - "... I reviewed this lady in Professor Dusheiko's clinic on 9.7.98...who acquired hepatitis C from screened blood transfusion... Subsequent investigations have revealed that the donor was PCR Positive for HCV RNA..."

A copy of the letter is attached and labelled WITN3286006.

- 17. Although many years have passed since we were first told that Maureen was hepatitis C positive, for me the anger and pain is as fresh as the day we found out.
- 18. After Maureen's hepatitis C diagnosis we were seen by Dr Richard Marley at the Royal Free Hospital. Dr Richard Marley explained the nature of the disease and the possible complications. The risks of liver

cancer and cirrhosis developing in the future were also discussed with us.

19. Maureen was advised to avoid alcohol, the risks of intravenous drug abuse was explained, and the risks of casual sex and tattooing were also explained. Of course, these did not apply to Maureen. Maureen was also advised to be careful if she ever had a cut/ bleeding graze and was told not to share her toothbrush.

## Section 3. Other Infections

20. None that we are aware of.

#### **Section 4. Consent**

- 21. Maureen and I were only made aware of the blood transfusion after Maureen's surgery, when we asked whether the operation went well. It was at this point that the doctors told us that Maureen was given a blood transfuse, and that Maureen could have possibly managed without having the blood transfusion, but would have taken a little longer to recover.
- 22. At no point did the doctors advise that the blood transfused might potentially be contaminated.

#### Section 5. Impact

23. Prior to Maureen's infection we were a very active family who often went on camping and skiing holidays with our children. Maureen and I also went back-packing around Australia and Scotland. However, this all changed when Maureen became ill, for example, Maureen and I had planned to travel to Thailand to visit our family, but the consultant advised that it was not safe for Maureen to travel as she was very weak.

- 24. Maureen loved the outdoor life and was always happy taking the dog for long walks, feeding her ducks and spending time with family but she could no longer do so as she was too ill and fragile to go out walking.
- 25. Towards the end of Maureen's life, she became very isolated as she suffered from bladder issues due to the pressure from the fluid on her stomach and therefore Maureen could no longer enjoy her outings to the garden centres, shopping, or visiting places of interest. Maureen also suffered with fluid accumulation on her legs and was required to give up driving. This made Maureen very dependent upon myself and children.
- 26. The effect Maureen's diagnosis had on our children cannot be put into words. Kerri and Lee devoted so much of their time to accompany their mother to hospital appointments for treatment. As a father and husband, I felt and still feel very angry to have witnessed the suffering my family have endured over the years.
- 27. Maureen died on 21 September 2018. The cause of Maureen's death was stated to be upper gastrointestinal bleeding of unknown origin and liver cirrhosis secondary to hepatitis C.
- 28.I felt as though I lost my wife the day we found out she had hepatitis C. Maureen was very cautious and fearful, and therefore decided to exclude any form of intimacy. Further, having witnessed Maureen get weaker and weaker by the day, is a pain that I cannot describe.

# Section 6. Treatment/Care/Support

29. In May 1997 Maureen was advised that the Pegylated Interferon Ribavirin treatment was available to her. We were told that the treatment involved having three injections a week for anything between 6 months and a year.

- 30. Although Maureen made the decision to go on the Pegylated treatment in May 1997 there was a delay of eight months because St Margaret's Hospital did not have sufficient funding for this treatment. As a consequence of the funding issues at St Margaret's Hospital, Maureen was required to undergo her treatment at the Royal Free Hospital. As such, I feel great sadness about the fact that Maureen *initially* considered to not take action against the hospital because she did not want to drain their financial resources. Further, the Royal Free Hospital is 29.3 miles away from our home and St Margaret's Hospital is 2 miles. This obviously had an effect on us financially and physically, given that at this point Maureen was very fatigued and fragile.
- 31. The Pegylated treatment itself was horrendous. The physical effects included skin irritation, nausea, and insomnia. Through the course of the treatment Maureen felt very tearful and she was constantly tired. I did not know if it was the fact of the illness or treatment but Maureen was very low, very anxious and seemed quite depressed. Maureen was not offered counselling or any psychological support.
- 32. Myself and my children were not offered any support after Maureen's diagnosis or even after Maureen died.
- 33. A few years after the Pegylated treatment, Maureen was troubled with pedal edema and abdominal swelling. Initially Maureen was advised to have a salt restricted diet and to limit her fluid intake to 2 litres. Further investigations were carried out and in 2011 the results confirmed that Maureen had developed chronic liver disease, namely cirrhosis. Maureen was put on medication for the cirrhosis which subsequently caused damage to her kidneys.
- 34. As a consequence of the cirrhosis Maureen was required to have a liver transplant. Maureen was on the active liver transplant waiting list for 5 months. On the 2nd August 2012 Maureen was given a liver transplant at the Royal Free Hospital. However, the liver transplant was

complicated by rejection, a bile leak and recurrent ascites. The doctors advised that the ascites was associated with a raised HVPG. Further, post-liver transplant Maureen continued to suffer from abdominal fluid accumulation which required draining and was therefore referred for ambulatory care.

35. Further, Maureen dreaded attending medical/ dental appointments as she knew it was essential to let clinicians know that she had Hepatitis C and therefore she avoided to attend any appointments if she possibly could.

### Section 7. Financial Assistance

36. Simon Hudson was advised that Skipton Fund offered financial assistance to those affected with Hepatitis C. As such, Kerri made an application to the Skipton Fund on Maureen's behalf. However, the Skipton Fund rejected Maureen's application on the basis that:

'...the Skipton Fund was set up by the Department of Health to provide ex-gratia payments to people who were thought to have been infected with hepatitis C as a result of receiving treatment with NHS blood or blood products prior to September 1991...'

A copy of the letter is attached and labelled WITN3286007.

- 37. Kerri was then advised to apply to the hepatitis C Trust but that application was also unsuccessful. We were informed that there were no prospects for compensation because Maureen did not meet the specific time criteria.
- 38. Kerri wrote to her local MP Sir Alan Haselhurst who advised he was not permitted by parliamentary protocol to act on Maureen's behalf as she was not a constituent of his.

- 39. We then sought the assistance of our local MP Mrs. Eleanor Laing. Mrs Laing then liaised with the Department of Health on Maureen's behalf, again, the Department of Health concluded that ex-gratia payments were only available to people who received infected blood products prior to September 1991. Therefore despite the fact that Maureen had been treated with infected blood, the fact that this took place in 1994 meant that she did not qualify for financial assistance from Skipton Fund.
- 40. The decision to not provide financial assistance was inevitably very upsetting for us all and made Maureen feel very angry. It seems unreasonable that those offering financial assistance to people who were affected or infected, did not feel able or willing to exercise some discretion to make an exception to grant financial assistance to Maureen. We did not and I still do not understand why the fact that this occurred in 1994 meant that Maureen was not entitled to some financial assistance.
- 41. My daughter Kerri made applications to the DWP for disability allowance and other financial support from the government, all of which were refused. An application for a disabled parking badge was successfully made, however, we received the parking badge in the post a week after Maureen died.
- 42. If we had received financial assistance over the last 25 years, we would have been able to make alterations to the house to assist Maureen, any financial support would have also hugely helped as it would have meant that Maureen could have spent more time with our children and myself, instead, she spent her last few years working. Also, Maureen would have died in peace, instead she died constantly worrying about our financial circumstances on her death bed.

# Statement of Truth

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

Signed GRO-C

Dated 22-8-19.