

Witness Name: Deborah Symmons

Statement No.: WITN0847001

Exhibits: **WITN0847002,**
WITN0847003, WITN0847004

Dated: 16th April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DEBORAH SYMMONS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 April 2019.

I, Deborah Symmons, will say as follows: -

Section 1. Introduction

1. My name is Deborah Symmons. My date of birth is GRO-C 1954 and my address is known to the Inquiry. I am Emeritus Professor of Rheumatology and Musculoskeletal Epidemiology, University of Manchester. My qualifications are MD MFPH FRCP. Until 2016 I worked as an honorary consultant rheumatologist.
2. I intend to speak about my infection with Hepatitis B and C in 1975. In particular I will describe the nature of the illnesses, how I was infected, how the illnesses affected me, how the diagnosis of Hepatitis C was made, and the impact it had on me. I will also describe briefly my

exposure to blood products potentially infected with the abnormal prion associated with Variant Creutzfeld Jakob Disease (vCJD).

Section 2. How Infected

3. I have von Willebrand's disease (vWD) which was diagnosed in around 1973, when I was a medical student, aged 19. This has subsequently been classified as Type 2M vWD from DNA testing in 2005. Other family members also have vWD: my brother, nephew, niece and two cousins. None of these is known to have received infected blood products.
4. Early in 1975, when I was aged 21 and a first year clinical medical student at the University of Birmingham, I was advised to have my wisdom teeth removed. The Birmingham Haemophilia Centre (Director Dr John Stuart) recommended that the teeth be removed one at a time, under general anaesthetic, and with clotting factor cover.
5. The first tooth was removed in April 1975 at Birmingham General Hospital with cryoprecipitate cover. I was an in-patient for two nights. This was the first time I had ever needed/received any clotting factors. All went smoothly and so it was decided to remove two teeth at the next procedure a month later. The plan was that I should have cryoprecipitate again, but the haematology senior house officer forgot to order it. Instead I was given freeze-dried Factor VIII concentrate (Kryobulin) which had been imported from Austria.
6. Exhibit **WITN0847002** is the product information sheet I received at the time. It is dated 04/02/1975. I was given this sheet by the nurse who set up the infusion. It mentions the risk of Hepatitis B (Hepatitis C was not known at that time). As a medical student I was aware that blood products carried a risk of Hepatitis B – but I did not realise how high the risk was with imported commercial pooled Factor VIII concentrate. I received this infusion in April 1975 before the publication in August

1975 of an article in The Lancet which described an outbreak of Hepatitis B and non-B associated with commercial pooled Factor VIII concentrate in Bournemouth (Dilling & Stern; Lancet August 2nd 1975 221-3), and before the transmission of the World in Action programme (in December 1975) about the high risk of hepatitis from pooled blood products.

7. About three weeks after the second dental extraction I developed severe nausea and vomiting, lost my appetite and became jaundiced. My GP performed blood tests, including liver function tests, and diagnosed acute hepatitis. I was sent home from University for two weeks. My father drove up to Birmingham to collect me. At home I rested, ate a bland diet and slowly recovered. When I returned to my studies the consultant that I was working with was concerned that I had developed hepatitis following the two dental procedures. He arranged for me to see a gastroenterologist (Dr Peter Dykes). The haematologists were informed (the senior registrar in Haematology was Dr Phil Gordon – I don't recall meeting a consultant haematologist at Birmingham General Hospital). Tests for Hepatitis B were negative. I was recommended to miss the last two weeks of term (when I would have been doing an introduction to obstetrics) and have an extended summer vacation.
8. My health recovered over the summer but on my return to University in September 1975 I experienced what was thought to be a relapse of the hepatitis. Once again I was anorexic, nauseated and jaundiced. My liver function was abnormal again, although not as marked as on the previous occasion. I was admitted to Birmingham General Hospital under the care of Dr Dykes. I remained in hospital for about a week. There was a discussion about whether I should have a liver biopsy or a course of steroids. However, on this occasion, tests for Hepatitis B were positive. My liver function tests returned to normal without any specific treatment over the next few weeks and I became Hepatitis B Surface Antigen negative. Once this had happened I had no further

follow-up from Dr Dykes, or the haematologists. However I did consult the haematologists in around 1977 about menorrhagia. No mention was made of the history of hepatitis at that time.

9. In 1978 I was working as a Senior House Officer in the regional infectious diseases unit at East Birmingham Hospital (now called Heartlands Hospital). One of the virologists working in the Regional Public Health Laboratory based at East Birmingham Hospital, Dr Ian Farrell, told me that they had some serum samples which had been taken during my two episodes of hepatitis in 1975. (He had recognised my name and asked whether I had had hepatitis in 1975). The samples had been re-tested, as part of a programme of work, and it was confirmed that the first was negative for Hepatitis B and the second positive. He told me that I had therefore had two separate infections: the first was 'non-A non-B Hepatitis' and the second Hepatitis B.
10. I don't know whether this programme of work had been instigated by the Regional Public Health Department or the Haematology Department but it suggests that there was local awareness of an outbreak of hepatitis at the time. As far as I am aware the results which Dr Farrell shared with me never found their way into my GP or hospital records.
11. Between 1981 and 1983 I was working at Guy's Hospital in London and registered with the Haemophilia Centre at Lewisham Hospital. I did not require any treatment during that time and was never seen by the Centre. I returned to Birmingham in 1983 to complete my rheumatology training. This brought me back in contact with the Haemophilia Centre at the Queen Elizabeth Hospital. By then Dr Ian Franklin was the Director. I finally had my fourth wisdom tooth removed at the Queen Elizabeth Hospital, Birmingham in around 1986 under local anaesthetic with Factor VIII cover.

12. I moved to Manchester to take up a consultant post in April 1989. I enrolled with the Haemophilia Centre at the Manchester Royal Infirmary in that year. (Hepatitis C was first identified in 1989). I had been following the medical literature and thought it was possible that I had had Hepatitis C in 1975. I asked to be tested in 1993 when making the arrangements for Factor VIII cover for a minor surgical procedure. The antibody test was positive (Exhibit **WITN0847003** Letter from Dr Guy Lucas). I asked to have the PCR test for the virus in 2001. The test has now been performed several times and has always been negative (Exhibit **WITN0847004** Letter from Dr Charles Hay). Tests for HIV have always been negative.
13. Although I was unlucky to have contracted Hepatitis B and C from only the second batch of Factor VIII I ever received, I was very fortunate that neither illness became chronic and that I cleared the viruses. I think it is quite likely that the Hepatitis C would never have been diagnosed if I had not sought the relevant tests as they became available. Some might argue that I would have been spared considerable anxiety over the years if I had continued to believe that I had had 'relapsing Hepatitis B' in 1975 rather than two separate forms of hepatitis, given that I remained well throughout that time and was Hepatitis C virus negative when finally tested by PCR.
14. However, statistically I was much more likely to have had chronic Hepatitis C and remained virus positive. If this had been the case I would not have been diagnosed until I became symptomatic with chronic liver disease, thus missing the opportunity for early treatment; and, also, I could have put others at risk if I had not modified my lifestyle. There appeared to be no record that I had received an infected batch of Factor VIII in 1975 nor that a retrospective diagnosis of non-A non-B Hepatitis had been made by 1978.
15. Given that there was obviously no central record of who had been exposed to infected blood products, I am surprised that there was no

effort at case finding even after it became clear that there were potential long-term sequelae to the hepatitis infection, and there was a screening test from 1989 onwards.

Section 3. Other Infections

16. All patients registered with the Manchester Haemophilia Comprehensive Care Centre received a standard letter from the Department of Health about variant Creutzfeld Jacob disease (vCJD) in September 2004. We received a further letter in February 2009 to inform us that a patient with haemophilia had been found to have the vCJD abnormal prion protein in his blood post-mortem. The patient did not die from vCJD and the finding of the prion protein was felt to be incidental. He was found to have received Factor VIII which had been prepared from a donor who went on to develop vCJD.
17. I was later contacted again and, at a clinic appointment, was told that I had also received Factor VIII from an implicated batch of pooled plasma. I was advised that I should inform the surgeon if I required any surgery as the instruments used may have to be destroyed as the vCJD prion is not eradicated by routine sterilisation.
18. I have received no updated information since then. I have since required foot surgery and a dental extraction. On both occasions I informed the surgeon of the possible risk. They seemed unconcerned. I suspect that, as time has gone by and there have been no new cases of vCJD for some time, the risk is now considered to be even lower than originally.
19. I think it would be helpful to issue new information to those people, such as myself, who were led to believe they might have become infected.

Section 4. Consent

20. I believe that I was tested without my knowledge or consent at the Regional Public Health Laboratory, East Birmingham at some time between 1975-8. However, it would not be the practice of a Public Health Department to seek consent. It is more relevant that I was not formally given the results of these tests and only learned of them as the result of a casual conversation.

Section 5. Impact

21. As a result of the acute infections, I missed around 6 weeks of my medical course in 1975. This had no long term impact as I passed all my exams and qualified as a doctor in 1977.

22. I was aware from 1978 to 2001 that I might be a chronic carrier of a hepatitis virus and so could potentially infect others. Little was known about non-A non-B hepatitis in 1978. Initially I knew that I had contracted it from a blood product but assumed that, as I had made a full recovery, the risk of me infecting others might be low. However, once my prior infection was identified as Hepatitis C in 1993 I became more worried as it was thought to be rare for people with a past infection to clear the virus. It was therefore a relief to discover in 2001 that I did not have any evidence of Hepatitis C in my blood stream.

23. I did not share the fact that I had vWD or that I had had both Hepatitis B and C (non-A non-B) with many people outside my family. I do not have a partner or children. As I was working for a University rather than the NHS from 1983 onwards, I never required a medical examination before seeing and treating patients. I did however require Hepatitis B immunisation and so I had my antibody levels checked periodically to show that I was still immune. In fact, the levels fell in around 2012 and I had a dose of Hepatitis B vaccine in order to boost them again.

24. I was advised not to drink alcohol at the time of the hepatitis infections. Feeling lucky that I had made a complete recovery and yet worried that my liver might have been damaged in some way by these two episodes of infection, I still do not drink alcohol.

25. I took out life insurance, without any additional weighting, when I was aged 24. I now have to pay an additional premium on my travel insurance because of the vWD but not because of the past history of hepatitis.

Section 6. Treatment/Care/Support

26. The treatment that I received for the acute episodes of hepatitis was readily accessed and appropriate. The treatment comprised of rest, a simple diet, no alcohol and monitoring of my liver function. I have not required any hepatitis-specific treatment or psychological support since 1975.

Section 7. Financial Assistance

27. I have not sought or needed any financial assistance.

Section 8. Other Issues

28. I have attached the product information for Kryobulin received in 1975 and two consultant letters. I have not sent for my medical records but would be willing to do so if it was felt that they might be of value to the inquiry.

Statement of Truth

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

Signed

GRO-C

Dated

16th April 2019