Witness Name: Ann Swan
Statement No.: WITN2042001
Exhibits: WITN2042002-WITN2042003
Dated: 11 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANN SWAN

Section 1. Introduction

I, Ann Margaret Deborah Swan, will say as follows: -

1. My date of birth and address are known to the Inquiry.

2. I am a Botanical Artist and Teacher with a studio in GRO-C, Wiltshire, and I travel widely, teaching around the UK and overseas.

3. I live with my partner Alan Watters and two miniature Schnauzers.

4. I am currently 13 months free from Hepatitis C having received the 12 week AbbVie 3D treatment at Chelsea and Westminster Hospital in September 2017 after being diagnosed with cirrhosis.

Section 2. How infected

5. On 17 August 1976 I collapsed at work at the offices of Phillips Electrical in London and was admitted as an emergency to the Middlesex Hospital, Mortimer Street, London with abdominal pain, vomiting and difficulty remaining conscious. I was placed on a drip and operated on the following day. A splenectomy was performed when it was discovered under anaesthetic that I had a ruptured spleen caused by blunt trauma received from a previous abusive partner.

6. I was given plasma as my blood group is unusual and therefore not normally available. This is not mentioned on my hospital discharge notice, WITN2042002.

7. During this hospital admission I was under the care of Professor Le Quesne, Surgical Registrar and D.M. Thomas F.R.C.S. at the Middlesex Hospital. My GP at that time Dr J Nally, 15, Museum Chambers, Bury Place, London WC1.

8. I was given infected blood products on 17/18th August 1976. I was discharged from the Middlesex Hospital on 26th August 1976. Approximately four to six weeks after discharge I became extremely tired and weak. I returned to the

Middlesex Accident and Emergency and I was told I had jaundice and to rest and avoid alcohol and fats. Which as far as I can recall I did and by January I was recovered and back at work according to my diary for that year. There are no GP records from this time apart from the discharge document which is dated 3 November 1976, nearly three months after my operation and after my subsequent bout of jaundice. There are no hospital records for this period either.

9. As a result of being given blood products I was infected with Hepatitis C (HCV).

10. I found out that I had been infected with HCV as follows. On 30 October 1995 I was to have a Cone Biopsy at the West Middlesex Hospital Day Surgery Unit. I was told seconds before being given a total anaesthetic for the operation that the reason I was the last person to go into the operating theatre was because of HCV. This was NOT mentioned in the letter I received prior to the operation, only that there was NO Hepatitis A or B, so this was the very first I knew of having the disease. On recovering from the anaesthetic I remembered being in shock and demanding to see someone to explain what this meant. The registrar told me that I had Hepatitis C and should contact my GP.

11. I was given no further information about HCV at the West Middlesex Hospital. I subsequently visited my GP, Dr GRO-D, Middlesex, and was told by him not to share my toothbrush, that I could pass on the infection through blood to blood contact, and that at least I knew what I was going to die from!

12. Dr GRO-D referred me to Dr Anderson at the Gastroenterology Department at West Middlesex Hospital. I was told I had Chronic Hepatitis C and that I should

take care about blood contact but sexual relationships were most probably OK. I asked what impact this diagnosis would have on my life expectancy and he told me that at that time they didn't know but I could have between five to ten years to live. This was a shock as I was only 46 years old at the time. I asked about treatment and he told me he was running a drug trial using Interferon which he could put me on.

13. I chose to investigate further myself and discovered that Interferon could cause serious depression, had unpleasant side-effects and I would possibly be unable to work for up to nine months. As I was self-employed by this time, this was not an option.

14. I refused to go on the Interferon treatment and after research discovered John Tindall, a Chinese Herbalist and Medicine Practitioner practising in Dulwich, who had done some excellent work with a Professor at St Mary's Hospital, Paddington, and was getting good results with HCV and HIV infected patients. I chose to privately fund this treatment for nearly 20 years in an effort to keep ahead of the disease.

15. I was not given adequate information to help me understand and manage the infection. Most of the information about treatments and research, symptom control and healthy lifestyle I discovered for myself.

16. I certainly consider that information should have been provided to me earlier. This should have happened as soon as infection was a possibility, i.e. when I became jaundiced in October/November 1976, four to six weeks after receiving the infected blood products. No further investigation was done at that time in October/November 1976 and all records have disappeared. However, during

that period up until I was told in 1995 of my diagnosis I believe I GRO-C

GRO-C

17. I also worked in an Observation and Assessment Centre with young children, then became a social worker specialising in work with children and families up until 1988, all this time carrying the infection without knowing I had it.

18. Throughout the period between 1976 and 1995 I had three long term relationships and all with unprotected sex.

19. When I received the diagnosis in 1995 I was given little information and no support. The implication was that it was just a fact that I had to accept and get on with my life as best I could. At this time, 1995, any news about HCV implied that it was mainly due to intravenous drug use and therefore there was a feeling of stigmatism and it was not to be talked about. Because I had chosen to take Chinese medicine I was just warned that this form of treatment carried risks.

20. The only information I was given about the risks of others being infected was not to share my toothbrush, to keep open wounds covered, and that protection during sex was a personal choice between myself and my partner.

Section 3. Other Infections

21. I do not believe that I have received any infection or infections other than HCV as a result of being given infected blood products.

Section 4. Consent

22. I do not know whether I have been treated or tested without my knowledge or consent. On 8 September 1995 I had a Colposcopy examination. Subsequently on 26 September 1995 I received a letter from West Middlesex, Colposcopy and Laser Clinic, James English, Senior Registrar stating:

    '*The blood that I took for Hepatitis A and B antibody levels report:- Hepatitis A – no evidence of recent or past infection with Hepatitis A virus and Hepatitis B – satisfactory antibody levels.*'

    There was no mention of HCC. One month later, on 30 October 1995, with no further tests being taken, seconds before my Cone Biopsy surgery I was told that I had in fact got 'Hepatitis C', these were the words she used, NOT 'Non A Non B'. I have no knowledge of when and how that was discovered.

Section 5. Impact

23. The mental and physical effects of being infected with HCV were as follows. In 1983 I first became ill with complete exhaustion, muscle weakness, swollen glands, brain fog and low grade temperature. I had repeated tests at the Royal Free Hospital in Hampstead and at Middlesex Hospital. I was told I possibly had a form of glandular fever but no definite results. I was ill for three months, recovered and returned to college. Then in September 1984 the illness returned with much more severe symptoms. I was often unable to walk very far or even get upstairs. Simple tasks like making a cup of tea exhausted me and I had constant brain fog, was unable to read or even watch TV at times. Further tests at Middlesex Hospital were again inconclusive. I was told I had a recurring viral

infection with liver malfunction in the early stages but nothing definite again. This time I was unable to work for at least seven months (whilst employed as a social worker).

24. I considered that I might have ME so I became involved with the West London ME group. These same symptoms returned in October 1988 and again I was off work for several months.

25. Throughout this period from 1983 I was experiencing regular periods of feeling really weak and exhausted. Exercise or tasks which I love such as gardening often resulted in a day in bed recovering so my life was quite restricted. The brain fog was a constant reoccurrence.

26. During this period I started drawing at times when I was feeling slightly stronger. Eventually in 1989 I decided that my health was not going to improve while doing stressful social work so I retired from work, just continuing with a short term group work project with Hillingdon, so I could concentrate on getting healthier and improving my artistic abilities.

27. By now even my GP had come round to the idea that I had ME so I treated myself as if I had ME, resting whenever necessary, good diet, low alcohol, gentle exercise, fresh air whenever possible. But I continued to have these low grade symptoms on and off. My new work life as a self-employed botanical artist enabled me to rest when needed.

28. After the HCV in 1995 I became depressed, I felt violated and toxic and began to feel very isolated. Because of the perceived stigma I felt unable to talk about my feelings with family and friends as you would if you had some other more

socially acceptable disease like diabetes for example. I asked my GP for a period of counselling which was granted and this helped me get things in perspective.

29. Throughout this time and right through to treatment in 2017 I had short periods of days, or in some cases three or four weeks at a time, of feeling exhausted and nauseous with headaches, brain fog and poor temperature control.

30. I researched alternative treatments and I started a course of Chinese herbal treatments with acupuncture which kept any symptoms under control. I also researched vitamins and minerals that would keep me as fit as possible so I could keep my immune systems boosted and try to keep the HCV virus at bay. I funded this line of treatment for the next twenty years.

31. I had a liver biopsy in 2002 which resulted in a blockage followed by jaundice and extreme pain for several days so I was unable to work for another two weeks.

32. A further biopsy in 2004 revealed minor liver damage. Thereafter I had regular ultrasound and fibroscans and blood tests which revealed only a slow progression of the disease. So I chose to continue on my treatment path and not have any NHS treatment which was still Interferon with Ribavirin and didn't offer a very high chance of a cure.

33. On moving to Wiltshire in 2006 the regular tests stopped and I no longer came under the West Middlesex Hospital. Eventually I asked for tests and was referred up to Chelsea and Westminster Hospital where my specialist was Dr Anderson who I first met at West Middlesex in 1995. My blood tests and scans

where still fairly OK and it was left up to me to decide if and when I needed further scans. Throughout this period my general health and energy levels were better and my artistic career prospered. In 2010 I wrote a book on botanical art which was well received. I then started a career teaching around the world. Life became very busy with much travelling but my health still gave me concern and I had to make sure that I had regular rest periods and a very healthy diet.

34. The further medical complications which have resulted from the infection include gallstones, which may or may not result from having a compromised liver. I also have poor bone density which I believe results from poor liver function as my calcium and vitamin D tests all proved normal. This has caused me some back problems for which I have private physiotherapy from time to time.

35. I received treatment for HCV in 2017. I had started to feel sluggish and bloated and decided to ask for a scan and blood tests. This time I had a new hepatologist at Chelsea and Westminster, Dr Verma, as Dr Anderson had retired. She didn't have any of my, by now copious, records and decided to start afresh with thorough blood tests and scans. This revealed early stage cirrhosis, which was a complete shock to me as my results had been fairly good up until 2015. She put me on an extremely restricted diet, no fat, no alcohol, no salt and absolutely no sugar, only slightly bitter berries, and I was offered the latest NHS treatment. I started this 12 week programme in September 2017 and the virus cleared within four weeks and has remained clear since. I am now considered cured.

36. In terms of any difficulties or obstacles in accessing treatment, I did experience some delay. In 2017, when I started to feel more unwell, I thought I might have

to fund this new treatment myself but, once it was discovered I had cirrhosis, Dr. Verma said she would put me forward for the NHS treatment. She said that her London area could only offer the new treatment to 15 patients a month and she would have to put my case up for consideration against many others. My understanding was that you can only qualify for NHS treatment if you have early stage cirrhosis. I was extremely lucky that I was offered treatment within a couple of months.

37. Also, all treatment, including blood tests, which I still have to have every six months, apparently can only be done in London. This means a day off work, a £100 round trip by train from Wiltshire for the tests followed by another for the results. In total since May 2017 I have had at least 17 trips to London, some requiring overnight stays plus one wasted trip as they had lost my results.

38. I do not believe there were any treatments which ought to have been offered to me which were not.

39. Apart from the many trips to London, I coped with the treatment very well and experienced no side effects, physical or mental. Subsequently now I am returned to full health I realise the impact that this disease has had on my life for over forty years. I can now exercise, walk for miles, garden all day long, eat well, and enjoy a glass of wine, all without any side effects or days in bed recovering. I also feel clean and part of the human race again.

40. Initially I felt sad when the virus finally cleared my system as it had been living with me not only in my body but in my mind for so long. It had been a constant battle for me to keep ahead of the virus both mentally and physically so when it finally went I did feel sad. This was followed by an immense feeling of joy and

belonging. I can only describe the sensation as no longer feeling like a secret leper.

41. My infected status has impacted upon my treatment. It is not pleasant to have every professional that has to touch you glove up for their own protection. Even my physiotherapist had to wear gloves to treat me and now I am cured she no longer needs to wear them.

42. The impact of my infection on my private, family and social life is difficult to quantify because this has been a long journey. When I suffered prolonged periods of illness, extreme weakness, depression and frustration it was difficult for my husband or subsequent partner to cope with. We have had to hire cars on holidays as I couldn't walk very far. Suffice it to say I was not much fun to live with.

43. Because of the perceived stigma of the disease I protected my family by hardly ever discussing it. I was just 'not feeling well' or I had 'overdone things'.

44. I have never experienced any problems with any professional other that from time to time the feeling that I was being a bit of a nuisance if I asked too many questions, plus a lack of support for my choice to seek alternative treatments such as Chinese medicine which I believe has kept me well for much longer than if I had just let the disease take its own course.

45. The infection has affected my education, my working life, and my finances. In terms of education, in January 1983, when I had my first bout of illness, I was studying for my CQSW social work qualification at Middlesex Polytechnic and I

missed the whole of the spring term at college and had to work really hard to catch up on returning.

46. Workwise, in 1988, after my final major bout of illness, I retired as a senior social worker to take up a less pressured and stressful occupation as a self-employed botanical artist. So if I hadn't had HCV I may never have become the artist I am today!

47. Financially, from 1984 to 1988 I was employed therefore periods of ill health were covered by sick pay. From 1988 until the present time I have been self-employed, so days off work missed as a result of poor health or travelling to London for tests and treatment have therefore resulted in lost earnings. From 1996 until 2017 I have financed alternative treatments consisting of Chinese herbs, acupuncture, physiotherapy, bone density scans and vitamin and mineral supplements, often totalling over £300 per month.

Section 6. Treatment/Care/Support

48. I faced a delay in obtaining treatment as I have described above. I have never been offered any care or support associated with HCV.

49. I have received counselling in consequence of being infected, but this was only at my request.

Section 7. Financial Assistance

50. I found out about the Skipton Fund through the media in August 2003, though I have never received any financial assistance through the Fund. I was unable

to submit an application as I didn't have any record of treatment with blood products. I contacted the Middlesex Hospital Assistant Health Records Manager, Kamil Yusuf, and was told that records for the period in question, 1976 when I had been operated on and subsequently became jaundiced, had been microfiched. I then contacted Dennis Dixon, Medical Legal Officer, and he told me there was no trace of my records. Subsequently, on 1 November 2005 my consultant Gastroenterologist, Dr Carole Collins at West Middlesex Hospital, wrote to Mr R Naylor, Chief Executive at The Middlesex Hospital, London saying,

'*I would be grateful if you could clarify whether the records have been archived or genuinely destroyed, as this has considerable financial implication for the patient.*'

She received no reply to this letter and kindly sent a further request to Mr R Naylor on 3 April 2006 asking again whether the notes had been destroyed or not and no reply was forthcoming to this letter. I have therefore been unable to confirm details of the blood products given and as a result unable to apply to the Skipton Fund. Copy correspondence from Dr Collins can be found at WITN2042003.

51. At that time, I put this loss of my records down to general incompetence on the part of the health service. I had a very poor experience of the medical profession then due to other previous operations when I was younger that had left me unable to have children. Fortunately, I have been able to support myself financially, although there have been some hard times, particularly when divorced and during the early years of self-employment when I was trying to build up a portfolio of work and establish a reputation as an artist.

52. There seems to be a huge amount missing from my general medical history prior to infection in 1976. Have these all gone to cover up what happened in 1976? There are also the missing records from the Middlesex Hospital at the time of infection in 1976.

Section 8. Other Issues

53. I would like the Inquiry to address the following issues: Why have records disappeared?; Have they been deliberately destroyed?; Why was this covered up?; Why were possibly infected patients not traced, warned and offered advice or treatment to avoid the risk to their own health and the risk of passing on the disease?; Why has this disease been allowed to spread so far?; Why are there still so many people believed to have been infected and why even now have they not been tracked down?; Now that the treatment has improved so drastically and drugs are available that can offer a 98% chance of a cure with only an 8 week treatment period why is this not offered to all?; Why do health budgets only allow a handful of patients to receive this life saving treatment?; Why can patients not be treated before they get to the stage of developing cirrhosis? I know the cost of drug development is high but surely with such large numbers who would benefit from treatment the costs should come down. Why is action not being taken to ensure this happens?

54. I hope the Inquiry will achieve a clear understanding of what has happened and why; an understanding of who was responsible and what was their motivation – was it all down to cost?; Once discovered, why has this huge problem been overlooked for so many decades? A full admission of culpability and a full apology needs to be given to those who have lost family members, whose lives have been blighted or shortened by this disease.

Statement of Truth

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

Signed

GRO-C

Dated 11 February 2019