13 MAR 2019

Witness Name: Neil James Ogden
Statement No.: WITN0318001
Exhibits: WITN0318002
Dated: 29th January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF NEIL JAMES OGDEN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23rd December 2018.

I, Neil James Ogden, will say as follows: -

Introduction

1. My name is Neil James Ogden. My date of birth is GRO-C 1960. My address is known to the Inquiry. I am semi-retired; I work between eight and ten hours per week at my former construction and roofing business. I started the business before 1991 and my son currently manages it. Before I set up the business, I worked as a Coalface Worker for National British Coal from the age of nineteen. I have been married for thirty-six years and have two grown up children who are aged thirty-four and thirty. I have a grandson.

2. I intend to speak about my experience of contracting Hepatitis C through a blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and our lives together.

How Infected

3. In 1977, at the age of seventeen, I was taken to Warrington General Hospital with a perforated ulcer. My parents and my sister, Vicky, attended. I was admitted to Ward 8, the main ward for general major operations. I was made aware that I was in a critical condition and I was taken to the operating theatre.

4. I had a haemorrhage when I was being transported back to the ward from theatre. I was taken to a private room and became seriously ill again. I was taken back to theatre where they found another ulcer under my liver. Whilst very scared I was fortunate to pull through. During this liver operation, I contracted an infection which was constantly weeping puss afterwards.

5. I was given blood and plasma transfusions immediately after the operation because I had lost a lot of blood. My bed sheets were covered in blood and I was also vomiting blood.

6. As I was seventeen years old, my mother had to sign the consent form. I understand that she was responsible for my treatment until I was eighteen years old. I was too ill to consent myself. I assume that the information regarding my treatment was given to my parents due to my age and my condition because the treatment I received was not explained to me. I do not now believe my parents were given sufficient information about the potential risks of contamination or exposure to infection prior to me being given the blood or plasma.

7. During the following fortnight, I had multiple surgeries for ulcers and abscesses. I had swollen legs and blood clots. I continued to contract infections that caused abscesses. I had a crisis because I was seriously sweating. I was aware that I remained on the critical list and was attached to lots of tubes.

8. Three consultants operated on me at Warrington General Hospital, where I understand they were based: Mr Johnson, Mr Heath and Mr Wilson. The Sister on the ward said that they were going to put me on a blocking agent. I was given blood and plasma transfusions throughout this ordeal. I then had more surgery for a perforated abscess.

9. My wounds would not heal; it seemed that there was just no recovery. The medical staff used an instrument that looked like a knitting needle, gauze and medication. However, whenever the wounds healed, they would perforate again. I did not think that I was going to live, especially as I witnessed approximately four or five people die around me each week. I was put in an isolation ward that had ten patients in it, rather than the normal ward with thirty beds. For a period of time, I was kept in constant sight of the nurses' station. I was in hospital for seven months and the medical staff gave me blood throughout this time. It is only through consulting my medical records later that I discovered just how much blood and plasma I was given. I am not sure exactly how much I was given but know it was a large amount.

10. I became fed up with my blood being tested three times a day. I was so ill in that period that I am now unable to recall the events in detail. I do remember the blood and the plasma drips. I was given more blood than plasma. I was given combined blood and plasma drips, as well as blood and plasma separately on other occasions.

11. I lost a lot of weight, but fortunately my wounds healed. I was left with a big scar, which took a year after being discharged from hospital to heal properly. I was embarrassed by the appearance of the scar to the extent that I was unable to go swimming. A number of years later, I went back to my GP and was referred to have the skin around this scar tidied up. I paid for this on a private basis.

12. This was a total nightmare but I was never referred back to Warrington General Hospital again, I was always sent to another hospital.

13. As far as I am aware, the only infection I contracted from the blood or plasma transfusions was Hepatitis C. I was diagnosed with Hepatitis C in 2014. I went to my GP because I kept getting blisters on my hands and my face. The blisters appeared particularly on the side of my face that was positioned towards the window whilst driving. My GP referred me to a dermatologist named Dr GRO-D at Western and St Helen's Hospital. Initially he gave me creams that did not work because the blisters were very sore, my skin was raw and the blisters kept growing. At my first appointment, Dr GRO-D told me that he could not find what was causing the blisters. I was very worried because my daughter was getting married at that time. Within three months of my first meeting with Dr GRO-D he conducted a blood test and told me that I had tested positive for the Hepatitis C virus.

14. As I was critically ill whilst was at Warrington General Hospital, I do not know from which particular blood or plasma transfusion I contracted Hepatitis C. However, I am certain that I was infected within this seven-month period in 1977.

15. I was not diagnosed with Hepatitis before 2014. I have never taken drugs and I do not believe in taking drugs unless doctors prescribe them. I have always looked after myself and have never abused my body. As a young lad I would have a drink but no more than my friends and contemporises. I do not believe that it likely that I contracted Hepatitis C when I was tattooed in the 1980s because of the hygiene safety practices that were in place at that time. This was largely due to the acute awareness of HIV and AIDS at the time. The tattooist used a new needle, sterilised the needle and wore proper gloves. The tattooist was very clean and maintained high standards.

16. I was very upset at the diagnosis but I did not know enough about Hepatitis C to fully understand what it meant. The dermatologist said that he was sorry that I had Hepatitis C because it is a terrible disease. I do not think that he gave me adequate information about it as he did not tell me what I should do or avoid. However, I do not want to criticise him as he referred me to the liver specialists. He did however tell me to stay out of the sun and prescribed a Factor 50 sun cream.

17. I read up about the risks of contaminating others. The doctor advised me to tell my dentist that I had Hepatitis C. However, I was not told about the risks of contaminating my wife and children; I had to research this independently. I learnt to live with the Hepatitis, however I was frightened about contaminating my family and wanted more information that I did not receive. GRO-C

18. I was transferred to a liver specialists and I remember one doctor called Dr Fox and someone else, a senior nurse called Paul. I was given five venesections and I went into shock when given the last one. The venesections involved taking pints of infected blood from me to allow my body to create new good blood. The liver specialists checked my records and discovered that I had probably been infected from the blood or plasma transfusions in 1977.

19. I began treatment for Hepatitis C six months after the diagnosis. I was given a twelve week course of Harvoni and Ribavirin tablets. I understood that this was a new form of treatment and I had to wait for it to become available. I think the doctors thought that the alternative treatment might have done more harm than good because they were concerned about my liver. I felt very ill whilst undergoing the treatment. I suffered from a loss of memory, was nauseous and suffered flu like symptoms.

Consent

20. I believe that I was tested for Hepatitis C without my knowledge and that the doctors knew I had Hepatitis C years before the dermatologist informed me.

21. After 1977, whenever I attended hospital I was always isolated in a private room. My family used to tell me that I was lucky to be in the private room, but in hindsight I now think that I was isolated to prevent other patients being infected by me.

22. Moreover, I regularly had blood tests after every operation. I also suffered with ailments including blood clots and kidney stones. Given the volume of tests that were carried out on me over the years, I find it very odd that they never picked up on the Hepatitis C. I now think that they knew but neglected to tell me. I think I was treated as some sort of guinea pig.

23. On one occasion around fifteen or twenty years ago, a consultant visited my hospital bed to ask if I was complaining about the management. This was in my mind completely unprovoked because I had not made a complaint and was always a good patient. The consultant said words to the effect of 'I know what is wrong with you; your blood is too thin'. Now thinking back, this strikes me as bizarre.

24. In regard to providing consent to the initial operations in 1977, I have spoken to my mother and I understand that my parents' attitude was to just get on with it. As they were born before the war it was not the norm to question doctors. It was accepted that you either made it through the treatment or you'd die.

25. My parents never told me that my treatment was for research, but looking back I think that the doctors must have known I had Hepatitis C. I was always scared of hospital infections afterwards. I had an inkling that I had been infected with something as I never felt quite the same again following the transfusions, but I was not told until 2014.

Impact

26. My liver is full of cirrhosis and I have liver stiffness. I have to have liver scans every six months. Some consultants have told me that I am fine now, whereas others have told me that I still have stagnant Hepatitis C in my system.

27. In 2013, I developed sore blisters that made the skin on my hands and face raw when exposed to UV rays. I was told the blisters are called Porphyria Cutanea Tarda. I still get blisters even after having received the treatment for Hepatitis C. I cannot travel abroad and I cannot spend time in the sun. This includes driving my car because of the risk of UV rays. I have to wear sunglasses, factor 50 sun cream and put UV filters in my car windows. The blisters leave white blemish scars, which are particularly visible on my arms. They are awfully painfully, especially when they bleed and burst. They do not heal easily.

28. Before I was told I had Hepatitis C, I could never stand sunlight and I would always wear sunglasses. I noticed that my eyes were yellow, which I now understand was jaundice. My eyes felt ill, they were heavy and I just did not feel like my former self

29. I was tired and sleeping all of the time. I would fall asleep in the middle of a meal and would not be aware of what happened. I have slept many nights in my armchair without knowing I had done so. I suffer with memory loss, which has greatly affected my professional and personal life. I also had lots of dizzy spells. I have had to learn to live with this.

30. Despite always taking care of my teeth, I have lost eight teeth. Wearing false teeth make me feel nauseous and I do not want to wear them. I am having private cosmetic dental surgery to correct this, largely due to the cost of individual dentist appointments.

31. My health was never the same after the operations in 1977; something always appeared to be wrong. I had an illness or a pain one after the other from the age of seventeen until five years ago. Around 1991, I was admitted to Warrington General Hospital for nine or ten weeks because one of my kidneys stopped functions due to the fact I have a duplex kidney. This means that I have a 'double kidney' on one side which can weaken the single kidney. I think they should have operated on it to improve my quality of life, however they decided against it. Looking back now I think there was something suspicious going on, however I am unable to identify what.

32. I was hospitalised in 1998 with kidney stones and received treatment at Wythenshawe Hospital in Manchester to break the stone into smaller parts. It took many years for me to pass these partial stones, which was very painful. I had a knee replacement operation in July 2018.

33. I have suffered a lot with blood clots. I had a particularly large blood clot in my leg. I have suffered with ulcers and stomach aches. I think Hepatitis C made me feel generally unwell for many years. For example, I used to have a lot of headaches. I knew that something was wrong but I had no idea that it was so serious.

34. Since the diagnosis and being treated for Hepatitis C, my life has improved, even though I have not been completely physically well. I feel that had I not

had Hepatitis C or been treated sooner, my other medical problems would have been easier to deal with.

35. My life will never be the same as it was before 1977. The Hepatitis C has left me particularly vulnerable to liver cancer and liver failure. I am therefore scared that I will develop these in the future. I feel that I just have to keep going. I am always frightened of the results following my scan. Even when the results bring me relief, I then become frightened of the next one. Often I just do not want to know the results and I feel like I am living on borrowed time.

36. I do not like having to lie down in hospital because I always want to get out. The quicker I am able to get up and walk, the better. Being so ill has been stressful.

37. Hepatitis C greatly affected my professional work. The loss of memory meant that I would visit a site to give a quote on construction or roofing work and then forget what I had said. I used to travel to a job that I had previously been to and forget how to travel there again. This was largely after I was diagnosed. I had to greatly reduce my hours, which was disappointing because I have always worked and I like to help others.

38. Since I was diagnosed with Hepatitis C, I have also noticed my memory loss affecting my personal life. I cannot now remember my twenty-fifth wedding anniversary celebration. Irrational things were happening to me but I cannot remember them. I was daydreaming all the time. My wife told me that I had got out of bed and walked around outside without clothes on, which I cannot remember doing.

39. I suffer with severe depression and I have mood swings that change daily. I always worry about what the next year will bring. I passed my company to my son and expected him to do better. I put him under extreme pressure and didn't allow him turn off. I did not realise that this was an illness; I thought it was just me. At the time, I did not realise that it was as bad as it was. I never thought much of the Hepatitis C when I was first diagnosed, but my wife took me to see my GP in 2018 and I was diagnosed with depression. There were times when I wanted to be on my own. I felt so small and dirty and had suicidal thoughts once. Fortunately, I am strong-minded and these thoughts did not result in any action. It is scary to think about it, but I cannot stop these thoughts coming into my head.

40. Around 2011, before I was diagnosed with Hepatitis C, I would get out of bed at night and do unusual things including taking mirrors off of the walls. I acted out of character, this included shouting at and hitting my wife. It scared me because I could not recall doing these things and I did not know I had done them until my wife told me.

41. My relationship with my wife has also been affected. GRO-C GRO-C GRO-C Our relationship has never been the same. This has

destroyed me. Luckily my wife has helped care for me and she has always been house-proud.

42. This ordeal has been particularly hard on my children and my grandson. I do not participate in activities that I used to with them, including eating in restaurants and going on holidays. I think this is silly of me, but I find it hard work and I cannot be bothered. I try my best to show emotion to my grandson by giving him Christmas presents. GRO-D GRO-D I am aware that my wife does more for him than I do. I know that I should be doing more with him.

43. My daughter got married in GRO-C 2014. The wedding was lovely however due to the blisters on my face and my hands, I had to wear makeup and gloves.

44. I regret telling some of my friends and family members about having Hepatitis C. I believe that it is my duty to let others know. I told GRO-D and just four weeks ago he told me that I could not visit him or his family anymore because I could contaminate his children. I felt that I had to tell them, but I regret doing so. I have cocooned myself away from my friends. I used to get on with people but since being infected, I have pulled the reigns back a bit. I also think that people are keeping away from me and some used to say evil words about me.

45. There is definitely a stigma of having Hepatitis C because people are worried about being infected by me. I have never slept around or taken drugs, but people talk and speculate about how I was infected. If my family and I had to move house, I do not know where we would go. Since this Inquiry has started, my family have received telephone calls from the media. I am worried and paranoid that my wife may say something by mistake when they call and the press will find out and expose my name.

46. I felt dirty when I went to the dentist. This was a dentist I had used for many years. Understandably he wanted to know what my liver count was once I told him I had Hepatitis C. However I was unable to give him a figure as I had not been given this information myself. The dentist respected me, but every tool he used in my mouth was put in a bag for sterilisation and they would not see patients after my appointment. I feel embarrassed and like an alien. He told me he'd had to decontaminate the room after treating me.

47. I was told that I could not go near farm animals following the diagnosis as the Hepatitis C made me vulnerable to contracting further diseases that could kill me. My pigs and livestock had to be slaughtered and I had to rehome my shire horses.

48. I am not able to go on holiday anymore. I once got ill on holiday and since then cannot go in the sun. I have to stay in the shade and I cannot play on the beach with my grandson. I used to love going away with my family and being in the sun, but am unable to expose myself to UV rays anymore. This was the case even before I started to get the blisters.

Treatment/Care/Support

49. I do not feel the doctors have been open with me. I am keen to have the information, but the doctors have not given me any explanations in plain English. I do not understand why they cannot be honest with me because I am living in dread. I could never get the truth as to the state of my liver beyond being told that it was bad news.

50. The liver specialists at St. Helen's Hospital treated me differently when I attended appointments alone rather than with my wife. They have asked me if I had slept around. I feel that I was treated as dirty when my wife was not there. Paul, one of the liver nurses, said 'watch the women, they'll share you' in a sarcastic way. Another liver nurse names Joanne Jones had a negative attitude towards me. She was not caring or professional and said various unpleasant things. She also refused to help me with my Skipton Fund forms. I do not know if they realised how such personal comments affected me, especially as I have been married for years. I felt that the liver specialists were making presumptions about my life that they were not entitled to make. Personally, I think I was treated badly because they thought I infected myself and they were denying and covering up the fact that I had been infected through a blood or plasma transfusion.

51. My relationship with Dr Fox at Whiston Hospital and Liverpool Hospital broke down after he refused to complete forms for the Skipton Fund. When I was first diagnosed with Hepatitis C, Dr Fox told me to 'do as I am told', I do not know what he meant by that. It is not my fault that I had been contaminated. I have always respected the NHS, I just wanted some respect back.

52. In the end I felt so uncomfortable seeing the liver specialists that I stopped my wife from attending appointments with me because I did not want her to hear what they were saying. My wife was very upset by it all and I did not want her to get more upset, especially because she had the children to worry about. This caused my wife and I to fall out.

53. After this, my relationship with the liver specialists went rapidly downhill and then broke down GRO-D a liver nurse, told me my appointment was an hour later than my paperwork stated it was. The appointments I was given were normally towards the end of their working day. The reason I was given was that other patients had more urgent conditions. I do not know if this was correct, however I wold say the staff at that time were under a lot of pressure.

54. I just want honesty and for an answer as to why I contracted Hepatitis C through a blood or plasma transfusion. I want this all to come to an end.

55. I have never been offered any counselling or psychological support. I felt I just had to go along with things and manage. There are times where you don't manage.

Financial Assistance

56. The only financial assistance I have received is from the Skipton Fund. I first found out about the Skipton Fund because a nurse or doctor may have mentioned it. The Skipton Fund contacted me and I was asked to complete forms. I later sent all of my records from Warrington General Hospital to the Skipton Fund.

57. I received a one off payment of £20,000 on 18th June 2015. I then received a monthly payment of £252.50. I do not know if any conditions were imposed because my wife deals with the financial assistance because I cannot be bothered by it. Due to a special category mechanism, my monthly payments increased to £1262.50 and this was backdated to 2nd October 2017. I am currently receiving £1862 per month due to my low income.

58. The monthly payment is now paid by the England Infected Blood Support Scheme (EIBSS). When EIBSS took over from the Skipton Fund, I applied for a stage two payment. However, my application was not successful.

59. The application procedure was a nightmare because I was sent from pillar to post. I went back to the hospital twice to ask them to complete the forms. The liver specialists sent me back to my GP. However, my GP told me that Dr Fox at Whiston Hospital and Liverpool Hospital would need to complete the forms. Dr Fox's attitude was that he was unwilling to complete any forms that were for financial gain. This upset me because I have always paid into the system and have never claimed benefits, but I was treated like I just wanted money out of the system. My relationship with Dr Fox broke down after this. Nobody ever helped me and I would never let him treat me again. I do not want to be disrespectful but his attitude towards ill patients was terrible. If people had respected us in the first place, I do not think I would have taken it as hard. The other liver specialists knew what the Skipton Fund was and their attitude followed Dr Fox's. This caused a lot of arguments between my wife and I because she wanted to get this sorted and I just wanted to get better. The medical part of the application process was completed by a junior nurse called Kerry

60. Joanne Jones, one of the liver nurses, appeared to be the second person in authority after Dr Fox. Her attitude and body language was never the same after I asked her to help me to fill in the forms. She was never caring or professional and she said unpleasant things. I could not get any answers and the liver specialists would not help me with the Skipton Fund forms.

61. The amount of money I have received is not sufficient. My life is ruined. My wife's life is ruined. My children and grandchild's lives could have been ruined had they been infected. I do not know what the future is going to bring.

62. I am always cold so my electricity bills are high. I had to put diesel heating in the house because I am always cold, especially my hands. Then my wife complains that the house is too warm. My regular hospital and blood test

appointments mean I have to pay for petrol and three or four pounds for parking. I had to give up work because I was not interested in it anymore and wanted to be left alone. I will have to pay to have cosmetic dental surgery and for regular dental appointments. The surgery will cost £6,200 and each dentist appointment has been between £300 and £400.

Other Issues

63. I have not been part of any other Inquiry. I have not been involved in any pressure groups or campaigns because I have always tried to keep a low profile because I was infected with Hepatitis C.

64. I exhibit a letter from Dr Fox dated 24th February 2016, which briefly explains my medical history, as exhibit WITN0318002.

Statement of Truth

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

Signed GRO-C

Dated 5.3.19