

Witness Name: Diane Margaret Folkard

Statement No: WITN4127001

Exhibits: **WITN4127002-004**

Dated: 28 October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DIANE MARGARET FOLKARD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 April 2020.

I, Diane Folkard, will say as follows: -

Section 1. Introduction

1. My name is Diane Margaret Folkard. My maiden name is Diane Ward.

My date of birth is GRO-C 1988. My address is GRO-C

GRO-C. I am from GRO-C

2. I have a husband and two daughters, GRO-C who is seven years old and GRO-C who is 16 months. I am a full time mother. My husband, Kieran is a full-time carer GRO-C
3. I intend to speak about my infection with Hepatitis C (Hep C) In particular, the nature of my illness, how I contracted it shortly after being born and how the illness affected me. I will also speak about the treatment received and the impact it has had on both mine, and my family's lives together.
4. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am not seeking anonymity as I wish for my story to be known in full.
5. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

Section 2. How Infected

6. I was born as the first of triplets during an emergency C-section caused by a premature rupture of membranes. Sadly, one of my sisters' died.

GRO-C

GRO-C

7. I was born prematurely with severe anaemia. As I grew older I was told that I had received blood transfusions to restore my immunoglobulin levels. My mum remembers going into labour, but I am not sure that she remembers me receiving the transfusions. My dad wasn't allowed to go into the ward.
8. Upon reviewing my medical notes received from Arrowe Park Hospital, I can see that I received a total of eight transfusions which were as follows:
 9. 11 July 1988 - blood pack number 247827K7
 - 13 July 1988 - blood pack number 671744K6
 - 20 July 1988 - blood pack number 356322K7
 - 31 July 1988 - blood pack number 248846K9
 - 6 August 1988 - blood pack number 357209K9
 - 19 August 1988 - blood pack number 172072K4
 - 24 August 1988 - blood pack number 250655K6
 - 27 August 1988 - blood pack number 451002KX

10. I received the first transfusion at 8 days old; the full details of which are contained within the copy of my hospital records when I was born.

Exhibited as **WITN4127002**.

11. I met my husband after graduating from University in 2010. We settled down in a life together. At that stage my health was fine, I had no knowledge or inclination that I was carrying Hep C. I therefore took no precautions to protect him or any other members of my family.

12. I then fell pregnant in 2012, as far as I remember the pregnancy was normal and I was at full term. I went into labour at home and was admitted to Arrowe Park hospital, Arrowe Park Road Upton, Wirral, Merseyside, CH49 5PE.

13. After a lot of pushing which lasted for over 12 hours it was decided that I needed an emergency C-section. My daughter, **GRO-C** was born on **GRO-C** **GRO-C** 2013. I can't remember half of it to be honest. I passed out for 3-4 hours and woke up with my baby beside me.

14. In February or March 2019, during the pregnancy of my second daughter, I was again admitted into Arrowe Park Hospital, this time with a bout of pneumonia. I had what I call an 'itchy liver' alongside a rash all over my stomach. However, during pregnancy it can be normal to suffer with skin problems so I didn't think much of it. I had also

sustained bruising to my ribs. It was at this point that the doctors performed some blood tests.

15. During this spell in hospital my husband and I were taken into a side room, which I thought was a bit strange. The nurse asked me whether I was aware that I had Hepatitis C. I literally went white in the face and looked at my husband in shock. I was really annoyed and swore at the time.

16. The nurse went on to ask me whether I used needles or whether I had any other sexual partners. I told her that I did not have any tattoos nor had I used intravenous drugs or received treatment abroad. I also informed her that I had one other sexual partner around 10 years ago during which I used precautions. I also explained that I was not a heavy drinker.

17. I had a healthy social life whilst I was at university several years ago, where I consumed alcohol one or two nights a week. The nurse then asked if I had received any blood transfusions to which I replied that I had been given transfusions as a baby. She confirmed that this was probably the likely source of transmission.

18. After my diagnosis, I knew I had to find out how I had contracted it. I started researching Hep C on the internet. I was convinced that it was caused by one of the transfusions I received as a child. I also had an operation when I was 9 months old at Myrtle Street hospital to repair a

valve between my heart and lung. I do not know whether I received a transfusion for this.

19. I don't understand how it wasn't detected earlier. I had an emergency C-section with **GRO-C** 6 or 7 years ago. I also had numerous blood tests over the years. I wonder what on earth would have happened to me had it not been detected last year.

20. I was advised to be careful if I had a cut and experienced bleeding. I found this slightly patronising as I had been careful anyway. I have been with my GP for almost ten years. He advised me that symptoms can vary from person to person. I asked him whether the side-effects of Hepatitis C can still develop following treatment. We have never discussed the Hep C to any great detail.

21

GRO-C

22

GRO-C

23. I was referred to the hepatology clinic to see a specialist mid-wife as the virus had been discovered towards the end of my pregnancy. After I had given birth I was given a fibro scan which revealed only minimal liver damage and that I did not have chronic liver disease.

Section 3. Other Infections

24. I presume that have I been tested for HIV and that this is negative.

Section 4. Consent

25. Prior to my diagnosis, although I was aware that my liver function was being tested, I was never informed that I was being tested for Hepatitis C.

26. As iterated above, I assume that I have been tested for HIV because it is also a blood borne virus. No one has expressed concerns that I might have contracted any virus other than Hep C.

27. I consented to the treatment I received for Hepatitis C.

Section 5. Impact

28. When I was first diagnosed with Hepatitis C, I put it to the back of my mind. I wasn't really thinking about it properly because throughout the pregnancy I was preoccupied with severe chest infections and acid reflux. Around the time of my pneumonia, I was also dealing with the loss of my nan. There were family arguments about housing and inheritance. It wasn't until 6 months after GRO-C was born that I began to feel sick with concern. Until then, I hadn't considered the ramifications of the infection. I began to wonder how I had contracted it and why me.

29. Growing up, I do not recall suffering from poor health. Nevertheless, I have always suffered from brain fog and fatigue. I don't know if that's due to being premature as a baby or as a result of Hepatitis C. I'm also severely anaemic which affects me intermittently. I only really began to notice the fatigue after the birth of GRO-C. However, I do not remember much of my childhood. It could be caused by a mixture of everything.

30. I also suffer from problems with my memory. I can be quite good at remembering certain things whereas others I will have to repeat over and over. It took me 11 times to pass my driving test. The last four times was actually because when I was reversing, the wheel hit the curb which is an automatic fail. My special awareness is quite bad.

31. Since I was about 12 years old, I have experienced stiffness and pain in my hands and my ankle joints. They feel weak even though I have never broken or fractured them. This has worsened over the last few years. I do not know whether this is caused by the anaemia or Hepatitis C although I have heard that the virus can cause rheumatoid arthritis.
32. I am currently attending Spire Murrayfield Hospital in the Wirral regarding respiratory issues and gynaecology. When my flow was particularly heavy, my anaemia was so bad that I would almost pass out. I do not know whether I have always suffered from anaemia or whether Hepatitis C might cause this.
33. I have not experienced problems with conceiving nor have I ever miscarried.
34. Over the years, I experienced bouts of dizziness where my vision would become disrupted and fuzzy for half an hour at a time. I would feel physically sick and fatigued. On one occasion I fell asleep in the middle of reading to GRO-C I was never able to put a finger on the cause of this.
35. I noticed a skin rash in the few months into my pregnancy with GRO-C. In the last year or two, I have also experienced sweating but this may be caused by diet, my anaemia, or fatigue. A few weeks ago, carrying my baby up and down the stairs caused me to feel absolutely exhausted.

36. I only recently found out that my anaemia has been on and off since 2017. I had my blood taken 2 weeks before my last cycle. Doctors thought that I might need another blood transfusion. I walked out of the appointment got to my car where my husband was waiting and started crying my eyes out.

37. I was in the middle of a heavy flow, which can cause me to become emotional but at the same time I was worried that I would be exposed to the risk of infection all over again. I'm now anxious to ensure that I maintain my iron levels so that I do not have to consider this route. They think I might have endometriosis.

38. Over the years I have experienced survivors' guilt because my sister died at birth and GRO-C yet I weighed the least and had more illnesses at birth. All I could think was, why am I here? Then of course, I discovered that I had Hepatitis C.

39. Having been diagnosed in Feb/March 2019, I did not begin treatment until after GRO-C's birth in GRO-C. I had also recently recovered from pneumonia. I was referred to the specialist blood nurse who interrogated me as to the possible sources of infection. I think the nurses were confused as to how I could have contracted a chronic infection at 32 years old.

40. On 11 July, I was seen by Dr T Conley, the SPR in Gastroenterology at Wirral University Teaching Hospital. My mother asked him whether the

blood transfusions I received as a child were the source of infection. He confirmed that they were 'certainly a risk factor for Hepatitis C transmission'. He advised me to take basic precautions and that my husband and GRO-C be tested GRO-C

41. He arranged for a genotype and Fibro scan which revealed an APR score of 0.238, which meant that I had a minimal risk of fibrosis. This is exhibited in a letter from Dr Conley to my GP, Dr Sinfield as exhibit WITN4127003.

42. On 26 September 2019, I began a 12-week course of treatment at the Hepatology Clinic in Arrowe Park Hospital. This involved taking one tablet of Epclusa once a day. I wasn't really advised about side-effects but simply read the brochures that were given to me. I didn't notice any difference to my health. I suffered from headaches but I don't know if this was caused by stress or the gynaecological problems that I suffer from.

43. I received ongoing blood tests to check whether the treatment was working. The nurse was very nice. At times, I felt as if she was treating me like a child. I don't think she was being patronising or judgmental but I think she had acquired a particular persona when treating patients with Hepatitis C.

44. After 12 weeks, I was given the all-clear. This was corroborated by a blood test three months after treatment. It was held that no further hepatology input was required and I was discharged.

45. I was relieved and felt fortunate that my liver was not in a worse state given I had a chronic infection undetected for 30 years. This is unless there are further problems lying dormant. This is a constant worry to me.

46. After being discharged by the Hepatologist at Arrowe Park Hospital, I have never had a discussion with my GP regarding the future of my care.

47. I have not experienced any problems with receiving dental treatment when I have disclosed my Hepatitis C status.

48. I have always suffered with problems maintaining friendships but this may be attributable to my anxiety.

49. GRO-C
GRO-C He
has been very supportive.

50. Following my diagnosis, I had to be careful with my children. I was more concerned with GRO-C at the time as she never leaves me alone.

She would follow me into the bathroom while I was changing. She loves to try to help. It was difficult to try to get her to stay away.

51. Since my diagnosis and discharge, I have to declare my Hep C status in hospital and dental appointments. It was brought up recently during one of my consultations at Spire Murrayfield Hospital for my respiratory problems. It makes me feel uncomfortable to think that all these years I've been saying that I am totally fine and now I have to say that I've had this in the past. I suffer from anxiety as it is. I worry that people will judge me and query how I contracted it, that they will think I have been sticking needles in my arms.

52. Earlier this year, I was given a flu jab at my GP's which I was eligible for, free of charge. This is unusual for a patient of thirty two years old. The nurse came out into the waiting room to enquire why I was receiving this. Luckily there were not any other patients present, however I was embarrassed to declare my Hep C status out in the open.

53. Whilst no medical professionals have been judgmental, I continue to feel dirty. It makes me feel dirty to think that I have suffered with a condition which has been undetected for all these years and which has been frowned upon for its association with drug use and the sex trade.

54. It makes my skin crawl. I would have kept it quiet if my GRO-D hadn't started sharing it with everyone. Initially GRO-D GRO-D because he works in medical negligence and I was in the process

of applying for EIBSS. Subsequently, she told a friend GRO-C as I was unwell with anaemia. I didn't expect her to share the minutia of my infection. It didn't feel very nice.

55. I don't remember struggling academically at school. I achieved B's and C's in my GCSES. I studied Business Studies, History and ICT at Birkenhead Sixth form College. However, I started having problems with writing, typing and grammar. I was always getting my words mixed up. I don't know if this was the result of a cognitive issue, the brain fog or perhaps the result of undiagnosed dyslexia.

56. I went to Liverpool Hope University to study Disability Studies. I think it was a complete waste of time. I have not been able to utilise this degree in the job market. I cannot hold a job down because I struggle too much. I suffer from brain fog and slowness. I can't seem to 'thread it together'. This causes anxiety. I do not know whether these are symptoms of Hepatitis C, my premature birth or the combination of the two.

57. I had a job at Timpsons in the last year or so which I could not retain as I had problems with multi-tasking. I became very confused and required more assistance than I should. I also found the customer service aspect challenging stressful and anxiety provoking.

58. My husband has been very supportive. At times, he gets annoyed that it was not detected earlier. He was quite upset as he always says that

he cannot live without me and was faced with the prospect that my life expectancy could have been shortened by this illness.

59. My parents are very angry that it wasn't detected sooner. My dad didn't really say anything but then he never really does. My mum was distraught. She kind of made it about her again. When I was discharged and seeking support from the EIBSS, she said, 'I wish it hadn't been you, I wish we'd been more supportive, we should have done other checks.' I'm not exactly sure what she meant by this. I think maybe she thought that she and my father should have interrogated doctors about my health when I was a child. I think she might blame herself. She blames herself for a lot of things. I try to reassure her that I needed to have a transfusion and this had nothing to do with her. Also, had I not had these transfusions, I wouldn't be here today.

60. I do not know whether my mother will ever come to terms with me having contracted Hep C. She still hasn't come to terms with my sister's death 32 years ago

GRO-C

GRO-C

61. Raising us was stressful,

GRO-C

GRO-C

. Then, last year my mother had to deal with the bombshell that her other daughter could have died from Hepatitis C.

62.

GRO-C

GRO-C

GRO-C This was the only occasion.

63. I have always wanted to donate blood. I knew I couldn't because I was aware that I had received blood transfusions as a child in the 1980s', which was connected with the AIDS epidemic. It makes me quite angry to find out that I can't do anything of the sort because I've been infected with Hepatitis C. I don't really like hospitals or needles, but the one thing I would like to do to help people is to give blood. I feel as if this has been taken away from me.

Section 6. Treatment/Care/Support

64. After the birth of my daughter and still in hospital I was advised to clean the toilets up after myself. I felt ostracised, as if I had been naughty. This was whilst I was still vomiting and trying to care for my new born baby with a fresh scar from the C-section. I am sure the nurses did not intend to come across as judgmental or nasty. It is not every day that they would have encountered a pregnant lady with Hepatitis C. Nevertheless, it wasn't nice to be made to feel like that.

65. I have never been offered any counselling or psychological support as a result of contracting Hepatitis C. I don't know if I need counselling in relation to this. I found out about the Hep C Trust by myself.

66. Sharon, the specialist blood nurse, advised me to contact the support groups. I made contact with the The Hepatitis C Trust, they were really good. I spoke to Sam who told me that my circumstances were quite unusual. She referred me to the EIBSS. I think she wants me to ring back to notify her that I've been successful in my application.

67. On the EIBSS website, I noticed that I may be eligible to apply for counselling. I have not applied for this.

68. I have received counselling intermittently for the past six months. This was for a different matter.

GRO-D

GRO-D

69. I cannot remember the majority of my childhood or my life until I met my husband in 2010. It is very hazy. My sister will ask me if I remember something and my mind goes completely blank. Prior to Covid, I received counselling face-to-face. It was emotionally draining as I was encouraged to remember painful childhood memories. During the pandemic, I received counselling over the phone. This was less effective than face-to-face treatment. My counsellor would also ring me up and I would be asleep half the time. My daughter was also

experiencing meltdowns half the time. I asked my counsellor if I could be temporarily discharged.

70

GRO-C

Section 7. Financial Assistance

71. My husband encouraged me to seek financial support for the Hepatitis C. I found out about EIBSS from the Hepatitis C trust. I completed the application online, the forms of which I printed and sent off in the post. I filled in my personal details including the name and contact details for the blood specialists by whom I have been treated and the name and contact of my GP.
72. I was also required to provide a particular reference number, which was only in the possession of my GP. This involved numerous trips back and forth to confirm that I had been under his care. I was required to provide photocopies of my medical notes, which detailed my symptoms and the transfusions I had received as a child.

73. My doctor's surgery charged me a £40 fee for completing my EIBSS application, which I wasn't very happy about.

74. The EIBSS responded within about 8 weeks. However, this involved persistent phone calls to check whether they were in possession of the documents that I had provided.

75. On 23 July 2020, I was informed that my application was successful. I was given a lumpsum of £20,000 alongside a monthly sum of £1,564.33. I am also given a winter fuel allowance of £540.

76. I am quite surprised that there were no arguments from the EIBSS about payment because it happened so long ago and I can't really prove for certain that I contracted Hepatitis C from the blood transfusions, albeit the documentation shows the pack number of the blood I was given as a baby. See **Exhibit WITN4127002**.

77. Initially, I didn't realise that I would receive this money for the rest of my life. It is both a relief to have monthly financial support and at the same time a kick in the teeth as it is a reminder of what has happened. I realise that I am only receiving this because I am not dead.

78. One of the documents I received from my GP was a dated 25 October 1988. Interestingly at point 4 it states, I received a total of 3 blood transfusions. **Exhibit WITN4127004**. This is contrary to my actual

hospital notes Exhibited as **WITN4127002**, which clearly shows I had 8 transfusions as detailed at Para 9 of my statement.

Section 8. Other Issues

79. I do not wish for anyone else to find themselves in the circumstances in which I have found myself. I still can't get my head around why it wasn't discovered sooner. Nobody can identify and explain why the Hepatitis C wasn't detected earlier in my case. Yet, what measures are being taken to prevent a similar situation from occurring in the future?

80. Over the years, prior to my diagnosis, I have had various liver tests, which revealed that my liver functioning was slightly abnormal. Yet I was told that there was nothing to worry about. No one noticed that there may be a problem worth investigating. This causes me to feel angry and frustrated. I fear the unknown, as I do not know how this will affect me in the future.

Statement of Truth

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

Signed

GRO-C

Dated

28/10/20