Witness Name: Tracey Loder
Statement No: WITN1353001
Exhibit: WITN1353002
Dated: 12th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF TRACEY LODER

I, Tracey Loder will say as follows:-

Section 1. Introduction

1. My name is Tracey Loder. My date of birth is the GRO-C 1968 and I live at GRO-C I have two children, Shannon Anne Zofia who is 24 years old and Bradley Charles who is 19 years old. I am employed by the NHS and I work as a Podiatrist.

2. This witness statement is made in relation to my late husband, Charles Loder (Charlie) who was born on the GRO-C 1965, and sadly passed away on the GRO-C 2009 as a result of contracting Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) through contaminated blood products.

3. This witness statement has been prepared with the benefit of access to some of Charlie's medical records.

Section 2. How affected

4. Charlie was born in Scotland and was diagnosed with severe Haemophilia A on the 4th May 1966 at GRO-C months old. He was admitted to the Royal Hospital for Sick Children (RHSC) in Glasgow as the doctors suspected he had pyogenic arthritis. When Charlie's knee was opened up he bled profusely, as a result he almost bled to death. The diagnosis of haemophilia was made.

5. Charlie's mother was a carrier; however, she did not know this as she was an orphan and was not aware of her family's medical history.

6. Charlie was treated at the Haemophilia & Thrombosis Centre at Glasgow Royal Infirmary (GRI) between 1966 and 1979. He was under the care of Professor Hutchinson and Professor G. C. Arnell. He was first treated with frozen plasma, and in later years with Cryoprecipitate (Cryo).

7. In 1973 he moved to Luton and in 1974 he had an appendectomy at the Luton and Dunstable University Hospital (the L&D). He was there under the care of Dr D. S. Thompson, Consultant Haematologist. He was treated with Cryo and Factor VIII concentrate. He received numerous treatments at the L&D and he was placed on weekly prophylactic treatment with concentrate.

8. From September 1979 to July 1980, Charlie attended the Lord Mayor Treloar College (the College), where he was treated with Hemofil, Factorate, Koate, Lister and Kryob. There is now produced and shown to me marked "Exhibit WITN1353002' details of the treatment Charlie received while he was at the College. This is also where he was placed on a trial for Factor VIII treatment.

9. At the College he was under the care of Dr A. Aronstam, Consultant Haematologist. He received his treatment there during term time; however, during school holidays and weekends he was treated at the L&D.

10. On the 2nd June 1980, the College noted that he was to be approached for a study of the half-life of a new preparation of Factor VIII. Unfortunately, his parents were provided with the wrong information in relation to the study. The notes from Dr Aronstam state that he had communicated with his parents in order to obtain their permission to approach their child for study and it stated: "I have erroneously stated that this project was on behalf of the Haemophilia Centre Directors of Great Britain. In fact, it is a project merely at the discussion stage in the working party on home therapy and prophylaxis. If parents do contact you about study I hope you would make this clear to them."

11. In July 1980 Charlie completed a course in self therapy at the College thereafter he was placed on home treatment. He started home treatment with Cryo.

12. When he returned to Glasgow in 1980, he administered Factor VIII at home. He remained in Glasgow until 1982. Dr Thompson at L&D had asked Dr C.R.M Prentice in Department of medicine at GRI to take over his care.

13. In June 1982, he moved to Gibraltar, where he lived until December 1983. He had treatment at St Barnard's Hospital, where he was seen by Dr Maskill, under the care of Dr Fitzpatrick.

14. He then moved back to Glasgow; however, in February 1984 GRI asked Manchester Royal Infirmary (MRI) to take over Charlie's care where he saw Dr GRO-D in March 1985. He was under the care of Dr Lowe, Consultant Haematologist at GRI

15. In later years he was under the care of Dr Charlie Hay at the MRI. He also had Factor VIII treatment in Blackpool Victoria Hospital (BVH) in May 1984 under the care of Dr Flanagan.

16. Charlie was never informed about the potential risk of infection from the blood products. His parents were only asked to give their consent for him to take part in the Factor VIII trial.

17. Charlie was infected with HIV and HCV as a result of being treated with contaminated blood.

18. Charlie was told by Dr GRO-D that he had HIV on the 1st July 1985, he was 19 almost 20 at the time. He was not given a lot of information about the infection other than he should use a sheath during sexual intercourse.

19. I do not think that he was given adequate information at the time.

20. He told me that he was taken into a room and Dr GRO-D told him about the diagnosis in a very blunt manner. Charlie got the impression that the doctor was trying to tell him that he was going to die.

21. I believe that more information should have been given to him a lot earlier to help him understand and manage the infection. He was very young and he could not take it all in and he went off the rails for a period of time.

22. In 1993, Charlie was told he had also been infected with HCV at the MRI, he was just told about it.

Section 3. Other Infections

23. I understand Charlie was also exposed to Variant Creutzfeldt–Jakob disease (CJD).

Section 4. Consent

24. To my knowledge I do not know if Charlie was treated or tested without his consent but given his reaction to the diagnosis of HIV it is possible that he was tested without his knowledge and consent.

Section 5. Impact

25. I met Charlie in 1985 when he moved to GRO-C where I was living. I had been seeing him for a couple of months when he was diagnosed with HIV. It was a massive shock to him and he did not deal well with the diagnosis. I recall he was cooking for me at his flat, it was a Tuesday evening and he just bolted. It was very hard for him. I did not see him for six months, I do not know where he went but perhaps he went to his mum's.

26. He took this time to try to come to terms with his diagnosis and what it meant to him.

27. He was being treated at MRI and I was at Salford University so we met up again in Manchester when he received treatment or when I came home at weekends to GRO-C. When we met up again he told me about everything that had happened.

28. He became destructive, he lashed out, he was angry and frustrated. He had addictive (gambling) tendencies, which I believe was his way of coping with the diagnosis.

29. Also he could not hold down a regular job, he was having two bleeds per week, and often spontaneous ones; he would wake up with new bleeds into his joints meaning he could not move an arm or leg. He could not extend his knees and his right arm could not fully extend.

30. When he was in Gibraltar Charlie worked in the docks. He was intelligent and was good at general knowledge even though he did not have much of an education.

31. I believe that his illnesses, particularly HIV, had a massive mental impact on him in the earlier years, and in the later years they affected him more physically.

32. As to the physical effects of his conditions, it was hard to spot any symptoms, as he was always a very ill person, so we did not see much of a difference until the very end, when he lost a lot of weight.

33. We moved in together in 1991 and we married on the 22nd May 1993. While I was working at Royal Lancaster Infirmary (RLI) in Podiatry, I was diagnosed with type 1 latex allergy, so we had to use latex-free condoms. We already had difficulties with close sexual contact due to Charlie's HIV and HCV, which resulted in us developing anxieties about him infecting me.

34. Latex-free condoms did not prove to be a successful method of protection as I became pregnant and Shannon was born on the GRO-C 1994.

35. When we discovered that I was pregnant we had mixed emotions, on the one hand we were pleased to start a family, but also we were anxious to find out whether I was infected, and in case if I was, whether I would have to terminate the pregnancy. Even my mum was furious at the time and told Charlie's mum I was a stupid girl!

36. We were denied the happy emotions of my pregnancy, and we could not tell our friends or work colleagues about it until I was certain. Shannon and I were both tested and thankfully we were HIV negative.

37. Charlie felt very guilty and we either abstained from sexual interactions or on occasions we were extremely careful. It made it very hard for us to have a natural and loving relationship.

38. Five years after Shannon was born I wanted another child. We had applied for in vitro fertilization (IVF) on the NHS but we were turned down as we already had a child.

39. GRO-C

40. Charlie was treated unsuccessfully with Pegylated Interferon and Ribavirin for HCV which caused him awful side-effects. He started to turn yellow; he was aggressive and was profoundly depressed.

41. He was also received treatment for HIV to which he had an allergic reaction, and made his liver condition worse.

42. He struggled with side effects of the treatments, such as depression, lethargy and mood-swings. He was like a ticking time bomb. I did understand him, he saw his friends die and he was afraid that he might be the next one to go.

43. As a result of his HCV, Charlie developed cirrhosis of the liver. He started becoming very unwell in 2008, his viral load was increasing so the hospital suggested dual therapy, but he developed an allergic reaction which seemed to kick start everything and his liver staring to fail. He became so unwell that by Christmas 2008 a liver transplant was recommended and he was placed on the transplant list in Leeds. Unfortunately he died on 12th March 2009, aged 43 in Leeds hospital. His death certificate states that the cause of death was liver cirrhosis, HCV and HIV coinfection.

44. In May 2006 I was diagnosed with HCV.

45. I suffered from various symptoms prior to being diagnosed. I recall studying the diabetes module at the University and being unable to stay awake. I also recall going out for a meal and throwing up. I originally thought that I had food poisoning. I was also desperately dehydrated.

46. My GP did some tests and I was admitted to the Blackpool Victoria Hospital (BVH) on the 20th May 2006, as my life was under threat due to the state of my liver. I then had a test for every possible disease, as the doctors could not believe that the severity of the damage to my liver was only due to HCV.

47. In a letter from Dr Charlie Hay to my GP of the 12th December 2007, he describes that I had severe, life-threatening, acute genotype 1 HCV, which is exactly the same as Charlie's.

48. Originally, I was not given any treatment as the doctors at the BVH said that I had spontaneously cleared it. However, I was not convinced.

49. When I went to one of Charlie's appointments with him at the MRI, his consultant asked whether he could take some blood samples from me to confirm that I had spontaneously cleared HCV. Test results proved that I still had HCV.

50. MRI had to apply for funding from North Lancashire PCT for me to have treatment at MRI and not BVH. The funding took time to come through but I was able to start treatment in September 2007.

51. I was treated at MRI and placed on Pegylated Interferon and Ribavirin for six months. Fortunately the treatment was successful and my HCV cleared.

52. Whilst I was receiving the treatment it was a very difficult period of time as the Interferon injections made me feel very sick, but I managed to continue to work.

53. At the time we had a lot of help from our parents, particularly with our children. Shannon was a competitive swimmer, and her training days started very early. Our parents helped us with that.

54. When Charlie passed away, Bradley would sleep at his grandparents' house a few times a week. This became normal for us, so that I could take Shannon to her early morning training sessions.

55. Due to the treatment I received for HCV, I developed tendon damage, which is a known side-effect. As a result I had to have two rotator cuff surgeries later one in 2014 at the Wrightington Hospital under Professor Funk.

56. I had to tell my employer, the NHS, about my infection as I was not sure I could work. I went through occupational health to tell my line manager, which was not easy. HCV made me turn very yellow, so I could not simply hide it.

57. As I was not a surgeon I was allowed to continue working with HCV. They were also very flexible. I had my Interferon injections on Fridays, so I was allowed to have Fridays off to cope with the side-effects. However I did four longer days which were tiring.

58. At the time Charlie was diagnosed with HIV there was a lot of stigma attached to the infection. We did not feel we could be open about it; we had to keep it very private, because of the stigma attached to it. Only our closest family knew about it. However we told our immediate family and close friends about my infection.

59. Charlie had four close friends who knew of his condition and they would play snooker together and attend quiz nights.

60. Charlie's illness and eventual death also affected our children tremendously.

61. Both of them, particularly Bradley, grew up without their dad. Bradley remembers very little of his dad, as he was only nine when Charlie passed away. Shannon was a bit older and she was always a 'daddy's girl', so losing her father affected her massively.

62. I feel a lot of pressure was put on her, particularly when Charlie was very unwell and I had to go to work. Shannon took a lot of responsibility of looking after Bradley.

63. Losing Charlie was also extremely difficult for his mother, he was her only child. She struggled with his loss greatly but Shannon and Bradley were her life. She passed away in January 2018.

64. As to the financial effects of Charlie's illnesses (including Haemophilia), he was never able to keep a stable job. As a result, he received a disability allowance and a mobility allowance.

Section 6. Treatment/Care/Support

65. I am not aware of any difficulties that Charlie encountered accessing treatment. I am also not aware as to whether there was any treatment available at the time that was not but should have been made available to him.

66. Charlie did have some problems getting the right treatment. He would go to the hospital and the doctors would say that they simply did not know what to treat him with.

67. We were originally not offered any counselling in relation to Charlie's illnesses. However, in about 1994, before Shannon was born, we were assigned a counsellor, Meg, from MRI who was very good. She introduced herself to us at one of Charlie's appointment's at MRI. She visited us at home and helped us to come to terms with what was happening and think about what we wanted as a family. Meg also told us about the benefits that we could apply for being disability living allowance and mobility allowance. She helped us till around 2000.

68. As very few people knew of Charlie's condition, it was good when we became a part of the Birch Grove Support Group which enabled us to attend events and talk with infected haemophiliacs and their families from the Manchester area. Our first meeting was in Manchester and Shannon was only couple months old.

69. It was originally set up by the patients of MRI and was a national support mechanism. Funding for the group was applied for from local government. The events dwindled off as year by year friends died.

70. It was great to have a support mechanism; however, at the same time it was very difficult to watch friends die.

71. Charlie had a close friend, GRO-A, at the MRI. They had spent a lot of time together. One day I was taking Shannon to her swimming training at around 5am, when I received a phone call from Charlie in a frantic state asking me to come and take him home, GRO-A just died.

Section 7. Financial Assistance

72. Meg told us about MacFarlane Trust (the Trust). I do not recall when exactly it was, but it must have been around the time when it was first set up.

73. Originally, we received small monthly payments from the Trust.

74. We also applied for a few grants for things for our home, such as double-glazing, but we were made to feel like we were begging for their help. We always had to justify the application by providing our income and doctors' letters.

75. When Charlie died, I received his monthly allowance for six months. I was told at the time that he had died in a wrong financial year, as from the following April the money increased dramatically.

76. As a widow, I received a children's allowance and we were entitled to grants for a computer and school clothing, as well as trips in the first year after Charlie died before cut backs were made.

77. I currently receive £250 per month for Bradley, plus £64 top-up per month. Although I have just been told today by EIBSS that I only now qualify for £64 a month top up!! There web site clearly states' I'm entitled to child payment until 18 or 21 in full time education!! But trying say he's living in UNI yes in term time but still my dependant and we received money through MFT I did for my daughter so now I'm £250 a month worse off which I can't afford to be and we were told widows would be no worse off with reforms!! I will have to look at selling my house now.

78. I was not entitled to widow's payments from the government because Charlie had not paid enough stamp. Luckily, I had a job and managed to pay the mortgage and childcare with help from grandparents.

79. After Charlie passed away, I received a lump sum of £10,000 from the Skipton Fund as a widow. As they had Charlie's details on their system, the application process was straight forward.

80. When I was diagnosed with HCV I applied for and eventually received a lump sum of £20,000 from England Infected Blood Support Scheme (EIBSS). The only issue that I had with the application was that when I applied for the stage one payment I was originally told that I was not entitled to it as I was told that the infection had cleared. However Dr Hay assisted me in the appeal process by re-testing me and the appeal was successful.

81. I have also tried to apply for widow's payment under the Scottish scheme, as Charlie was Scottish and had first been treated there. However the application was rejected because they could not identify where he had been infected. Also as he had applied to the Trust in England, I was only entitled to payments from the English scheme which resulted in a difference of about £2,000 less per month.

Section 8. Other Issues

82. I want the truth to come out of the Inquiry and justice for those who have died and have been infected.

Anonymity, disclosure and redaction

83. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

84. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed..........GRO-C......

Tracey Loder

Dated 12th April 2019