Witness Name: Mark Louis Stocks
Statement No: WITN1548001
Exhibits: 0
Dated: 21st January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF MARK LOUIS STOCKS

I, Mark Louis Stocks will say as follows:-

Section 1. Introduction

1. My name is Mark Louis Stocks. My date of birth is the GRO-C 1982 and I live at GRO-C with my wife, Kerrie, and our three sons, aged 5, 12 and 14. I work as a HGV driver.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

3. I was diagnosed as a severe Haemophiliac A when I was 8 or 9 months old by Dr Mark Winter at Guy's Hospital. I am that told I showed signs of having a bleeding disorder at birth, but the doctors thought that I had a haematoma as no one else in my family has Haemophilia. Since I was diagnosed with Haemophilia I have received blood products, one of which was Factor VIII.

4. I first received treatment for haemophilia at the Haemophilia Centre at Margate Hospital. I was later transferred to the Kent and Canterbury Hospital, where I was treated by Dr Mark Winter and Dr Gillian Evans.

5. When I was still very young probably late 1983, we moved to London and as my mother did not drive we could not travel to Margate Hospital whenever I needed a treatment so I attended Guy's Hospital instead.

6. When I was about 4 years old we moved to GRO-C therefore I returned to Margate Hospital for treatment.

7. I did not need treatment on a prophylactic basis; I only had it whenever I needed it, which was around once every couple of weeks, though sometimes on a weekly basis.

8. I have been told by my mother that she was never given any information or advice about any risk of being exposed to infection from blood products.

9. As a result of being treated with blood products, I have contracted Hepatitis C (HCV).

10. Prior to being diagnosed with HVC, I was tested for the Human Immunodeficiency Virus (HIV), which thankfully proved negative. It was a great relief, in particular for my mother.

11. I was told of my diagnosis with HCV in 1992 when I was about 10 years old. I attended bi-annual reviews at the Kent and Canterbury Hospital and it was during one those appointments that I was told by Dr Gillian Evans of my condition. Before the appointment it was known that I was being tested for inhibitors therefore it was a shock when the diagnosis of HCV was given to me. It was also a great disappointment, considering the stress already caused by the test for HIV.

12. I was told of the diagnosis in a very casual manner and as a result I believe I did not think much of my condition. My mother was thankful that I did not have HIV, and that was the focus.

13. At that time it appeared that nothing much was known about HCV and its effects. I do not recall being provided with any information about the infection at the meeting though I did at some point receive an information leaflet. I don't think I was given the leaflet at the appointment I think it was later. There was no deep discussion about the condition. Overall, I was not advised as to what was going to happen.

14. I did not really know what HCV meant until I formed a relationship with Kerrie in about 2000.

15. Further, I learnt more about what my HCV meant for me when I started receiving treatment in 2003. I believe that I should have been given more practical information before about my condition prior to receiving the treatment. Further, the hospital should have emphasised the importance of my infection when I was first told about it. This is so that I would understand the risks associated with the infection not only for my own purposes, but also so that I would be aware of the risks for other people. Looking back now, when I was a child I was very active and as with any child injuries occur. My mother tended to those open wounds and cuts without realising the risk associated with the injuries I sustained.

Section 3. Other Infections

16. I am not aware that I have any other infections.

Section 4. Consent

17. Whenever I had any tests undertaken it was assumed it was for my haemophilia condition, alternatively, the doctors would tell me or my parents that the tests

were for inhibitors. I do not recall being told specifically the reason for each test. I am not ware of any other tests being undertaken.

Section 5. Impact

18. In terms of the physical effects to me, the issue with HCV is that the effects of it are not apparent until later when the damage has already been done. At the moment I am ok, the condition is dormant due to the treatment I have received.

19. To my knowledge the virus has not had a major impact on my physical health, however the treatment I have received has had very severe, physical and psychological effects.

20. I was not offered any treatment for my condition initially. The first time I found out that treatment was available was when it was first offered to me in about 2003.

21. I do not know why I was not offered treatment earlier, I only recall being told that I had to wait until my HCV infection progressed to a certain stage in order to be treated. However, I believe that if there was a possibility of being treated earlier, I should have been given the chance to benefit from it. At the time I had no reason to question the doctors.

22. The treatment I received involved having chemotherapy type injections, using a pen type injector, which I self administered to my stomach once a day plus tablets 2 or 3 times a day. The treatment lasted a year and made me very unwell, it is a blank period to me as I do not remember most of it. I missed my 21st birthday which is mean to be a special occasion in everybody's life; instead I was deprived of it. I was too unwell to do even the most basic everyday tasks. I felt awful, I was very tired and miserable, I had no get up and go and spent a lot of time in bed. I lost a lot of weight and my daily routine consisted of waking up in the morning, eating and going back to sleep. I feel I have missed a year of my

life. I was not able to function properly during those 12 months and it took me sometime to recover.

23. As a result I had to give up my job as a chef meaning I had no income. Kerrie was expecting our first child so we had to move back to my parents' house. We were looking for our own home at the time and due to our situation we did apply for a Council property but as both our parents had three-bed houses our application was refused.

24. Kerrie and I had little income when we lived with my parents, I was in receipt of sickness benefit and that was it. We relied on my parents for financial support which put a strain on my parents' finances.

25. My treatment also led to a lot of emotional distress, not only to me, but also for Kerrie. As it was her first pregnancy, it was a difficult time for her, and instead of supporting her, I was an additional source of stress. It should have been an exciting time for us both instead it was miserable and stressful.

26. If I didn't have Kerrie and my family to support me it would have been a lot worse for me.

27. I found it frustrating that the treatment came at a time when I was building up a career as a chef, I had to give it up at an important time and I had this opportunity taken away from me. Instead, I have had to rely on other people to help me. I have therefore had to change what I was originally intending to do in life as a career and what I was always very passionate about.

28. Returning to work proved to be very challenging. I lost a significant amount of weight as a result of the treatment. Therefore, I could not return to work immediately after finishing my treatment, as I lost a lot of muscle strength, so I felt I could not physically do a lot.

29. I never had problems with confidence prior my treatment, however afterwards I felt very uncomfortable with how I looked and how weak I was, which also affected my confidence. It took me a long time before my confidence returned.

30. It took me months to pick myself up after the treatment so it took me time to find a job. I was afraid that potential employers would ask me the reason why I was unemployed for such a long period of time and I did not feel comfortable with the idea of sharing my illness with people.

31. Fortunately I was offered help from Kerrie's father, he gave me a job in drainage, as a sewer cleaner. He knew my situation and he did not question my prolonged unemployment. I remained in that job for 5 years.

32. Later when we were ready to buy a property, it was harder for us to get a mortgage, as I could not prove continuous employment. Therefore my parents lent us money to be able to provide a large deposit so it was easier to get a mortgage.

33. The treatment I received also seems to have had a detrimental effect on my stomach. I used to be a chef with a cast iron stomach and as a chef I enjoyed trying different food.

34. However now I have to be careful about what I eat. I never had any problems with my stomach before the treatment; yet after my treatment I am unable to retain food very well. Therefore, I need to be very careful with what I eat and where I eat it, as I need to ensure that I am near a toilet whenever I eat. This proves to be particularly difficult now that I work as a HGV driver, as a bathroom is not always readily available. I therefore often have to wait until I can stop somewhere in order to eat. This causes me to have to starve myself whilst driving, which can last for hours. This has also led a significant weight gain, as once I do get to stop to eat, I tend to overeat, in order to prevent myself from getting hungry whilst I am driving.

35. Further, as the treatment has not cleared the infection; it has made it dormant, it means that it might return at any time in the future, which is very stressful for me. My Mum worries about me too and I do not like being a burden on others.

36. I try to avoid telling people about my condition including my haemophilia. Other than my immediate family and closest friends, nobody else knows. I work on a 'needs-to-know' basis. This is because I know that there is still a lot of stigma attached to the illness, and I do not want people avoiding me because of it.

37. I left a job at a warehouse which I took as a 'stop-gap job'. However my employer wanted a letter from my doctor to prove that I was fit to work, I didn't go back.

Section 6. Treatment/Care/Support

38. As a teenager I was offered counselling but I tried to battle on without help.

39. I have also read in my medical records a note that my parents received counselling. I have asked my mother about it and she has said that she never received any counselling.

40. I am not certain whether there was counselling offered to me later, if it was, I doubt I would have taken it as I have the benefit of support from my family. I might have gone once to a session, but I am not sure.

41. I feel that perhaps the importance of counselling for the purpose of my mental well-being should have been emphasised to me, if it had I might have accepted the offer of help but I am not one to complain I just get on with my life.

42. I am also disappointed with the doctors and care following my treatment. I have had a number of tests done for my stomach complaint, but I am told there is no connection between the treatment I received and my current issues. I have tried

a number of different diets; however, none of them work, and the doctors have been unable to narrow it down to anything.

Section 7. Financial Assistance

43. I was not initially offered any financial help or assistance. I do not recall whether I was eventually contacted by someone or whether I was the one seeking the information; however, I found out that I was entitled to a free prescription card, which I had never previously been informed about.

44. I also came across the Skipton Fund, around 14/15 years ago perhaps through the Haemophilia Society. I applied for support and was awarded £20,000. I understand that the Skipton Fund was available long before I found out about it. It is disappointing that I did not know that financial support was available earlier.

45. I do not recall the process of applying for the fund, but I do not believe that it was particularly difficult. I think that the hospital might have helped me to apply for the award.

46. For the last two years I have also been receiving monthly payments from the England Infected Blood Support Scheme (EIBSS). The original payment was £3,000 per year but now it is £1,000. I also receive the winter fuel payments.

47. The application process to the EIBSS for the monthly payments was significantly more difficult and time-consuming than the other financial help I received. There was an entire booklet to fill in and many questions asked were repeated, or at least posed in a different way.

48. I have realised from my own observations and the information I have received, that the funds offered are not distributed equally and there are no clear reasons for the allocation of funds. I also do not believe that it is fair that people applying

for the financial help in Scotland and Wales get significantly more money than those in England.

Section 8. Other Issues

49. I am very disappointed with the doctors and the NHS. They knew about the risk of infection from blood products in the 70s. I was born in 1982, which is some time after the risk was known to them. Therefore, I should not have been treated with contaminated Factor VIII, I could have been saved from these traumatic events. Alternatively, my parents should have been informed about the potential risks associated with being treated with Factor VIII.

50. Also due to my condition, life, health and travel insurance would be either too expensive for me or it would be hard, if not impossible to get.

Anonymity, disclosure and redaction

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

52. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

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

Mark Louis Stocks

Dated 21st January 2019