Witness Name: AJ Tarren
Statement No: WITN0274001
Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANDREW JOHN TARREN

I, Andrew John Tarren, will say as follows:-

Section 1. Introduction

1. My name is Andrew John Tarren and I reside at GRO-C Lincolnshire, GRO-C. My date of birth is GRO-C 1968. This is a transitional period for me because I used to be a farm manager living in a tied house but following my poor health I had to leave this job in June 2018 and my girlfriend and I will shortly be moving in together. I am currently retraining to be a mortgage advisor.

2. **This statement has been prepared without the benefit of access to my full medical records.** I am missing 12 years of records between 1968 and 1980 from the Sheffield Children's Hospital where I was under the care of Dr Lilleyman. Furthermore, GRO-D GRO-D still hold a number of my other medical records which, despite repeated requests, have still not been released.

Section 2. How Infected

3. I have mild Haemophilia A with a clotting factor between 7-13 percent.

4. I received Factor VIII concentrate on two occasions during the 70's, those being Oxford Factor in 1971 during a hernia operation and BPL Factor in 1978 during a tooth extraction operation. A record of this is in my Lincoln notes as I was handed over from Sheffield.

5. On both occasions I was unconscious and the Factor VIII was given to me without my parent's knowledge and therefore without their consent.

6. I was infected with Hepatitis C as a result of receiving contaminated Factor VIII. I believe that I was infected in 1978 and I recall being and looking poorly in the 1980's. I have records showing infection explosion through blood testing after Factor VIII treatment.

7. I was treated at the Sheffield Children's Hospital from 1968 to 1980 under the care of Dr Lilleyman and at Lincoln County Hospital from 1980 to 1996 under the care of Dr Adelman and occasionally Dr Prangnell.

8. My parents accompanied me to all of my hospital appointments until I was aged 14 or 15.

9. As soon as I started attending appointments alone, I recall being told by Dr Adelman, in a very blasé way that all of the blood products came from Scotland and therefore there was no risk of infection. I feel knowledge of my infection was very evident, certainly during the early 80's. All blood laboratory work had risk of infection stamped on it. Also within my records I found a medical circular that stated young haemophiliacs that hadn't been given Factor viii or were mild should be given DDAVP or Cryo. This never happened and a very interesting file on 18.11.1992 stating I have never had DDAVP treatment and when I was tested I was around 35%. Good enough for mild bleeds which I commonly had.

10. Dr Adelman did not tell me that I had contracted Hepatitis C until 1995. However he had full knowledge January 1994 as more accurate testing had become available and this was carried out on stored bloods from 1990 (they had no permission to do this).

11. I comment briefly on the history that led to me being told about my Hepatitis C in 1995. I had been poorly for a number of years which involved in patient stays at the Lincoln County Hospital. I recall one such admission in 1990 when I weighed only 57 kilograms. I was unable to eat and had horrific back and abdominal pain. I actually looked anorexic. I was initially told that I had contracted Reiters Disease. I was then sent to the Genitourinary Medicine (GUM) Clinic as they suspected that I had contracted chlamydia. I certainly don't

recall being told that I was being tested for Hepatitis C at this time and I don't think the GUM clinic tested me for this.

12. However, I recall that somewhere in my medical records (which are held by GRO-D GRO-D), there is a record about a Hepatitis C test being carried out in or around 1990 at the Lincoln County Hospital but I don't believe that this was taken when I was at the GUM clinic and was instead taken during a routine clinic appointment. This test was carried out without my knowledge or consent. Strangely this result was negative, although I am aware that tests do sometimes produce false negative results. I understand that the bloods taken from me at this time were then sent to Scotland and stored and retested in January 1994. This was also without my knowledge or consent.

13. In or around 1994, Dr Adelman then took further bloods from me, without my knowledge or consent, to test me for Hepatitis C. I understand that these test results were positive for Hepatitis C.

14. During the Christmas of 1994 I became very unwell. I therefore telephoned the Lincoln County Hospital on or about 27th/28th December 1994 and spoke to Dr Prangnell. I think I described how I was feeling at the time and I assumed that he was well aware, by this time, that I had Hepatitis C. He told me that it sounded like I may have Hepatitis C and he asked me to book an appointment to see either him or Dr Adelman.

15. This appointment took place in January 1995 when I was tested and still not notified of my infection. Finally in February 1995 I had a follow up appointment and was told about my infection by Dr Adelman. He did not give me much information to allow me to either understand or manage my infection. He also told me that it was almost impossible to transmit the virus via sexual contact, about a 2% chance.

16. The Haemophilia Nurse, at Lincoln County Hospital actually told me a bit more about Hepatitis C. She was realistic and said that I would have to stop working and that there was no cure for this virus and that I would not recover from this. She said that I may require a liver transplant and that my prognosis may not be good. She then told me to get out of Lincoln County Hospital and return to Sheffield Hospital. She told me that they were not treating me appropriately at Lincoln County Hospital and I note that she herself ended up leaving Lincoln County Hospital because she did not agree with how we were treated. I did not have a good working relationship with Dr Adelman. I found him patronising and condescending and I felt he thought I was beneath him.

17. I have a lot of anger about the decisions made for me without any consideration for my wellbeing. As if I had known that my liver was abnormal I would have acted accordingly. All the facts should have been transparent.

Section 3. Other Infections

18. I received a letter, which I have not retained, in or around 2001/2002 confirming that I had been put at risk of vCJD in 1998. I injured my wrist in 1998 and received Factor VIII at Lincoln County Hospital, I went there as it was closer for treatment than Sheffield. Strangely Dr Adelman wrote and told Sheffield about the vCJD complication and a couple of years later asked sheffield for information about my vCJD status asking them when I was put at risk. This is noted within my medical records from Sheffield Hallamshire Hospital.

Section 4. Consent

19. I have no doubt that I was tested for Hepatitis B, Hepatitis C and HIV without my knowledge or consent.

20. With regard to the Hepatitis C testing I refer to paragraphs 11, 12 and 13 above. I had absolutely no idea that any Hepatitis C testing was taking place because nothing was ever discussed with me in this regard.

21. I believe that I was used for the purposes of research and an example of this is when my bloods were retained without my permission to which paragraph 12 and 14 above refers.

Section 5. Impact

22. I suffer from fibromyalgia, chronic fatigue, irritable bowel syndrome, depression and anxiety.

23. Every morning for the first hour of the day I feel terrible, wake up feeling like I have flu. The days vary sometimes I seldom have a good day but if I do it's always tinged with extreme tiredness. The fibro fog affects my mind and I am always feeling depressed and low. The affects in my body as a result of fibromyalgia is very painful.

24. I commenced a 7 month course of Interferon treatment in May 1995. I suffered with terrible side effects which included headaches and extreme exhaustion. I was very poorly and spent a lot of time in bed. Unlike many others, I did not suffer with any shivers. However, it was certainly not a nice place to be in mentally. Unfortunately the treatment was unsuccessful and I felt constantly drained and mentally unwell; it really hammered my body.

25. I was extremely fed up in general and also with the care I had been given under Dr Adelman at Lincoln County Hospital. In 1996 my GP Dr Burch asked if I would like to be referred to Sheffield Hallamshire Hospital as she felt I wasn't being given adequate treatment at Lincoln and a comprehensive centre would offer superior treatment. I was transferred to Sheffield Hospital almost straight away (in 1996) and was placed under the care of Professor Makris. He was fantastic and he restored confidence back which I had totally lost following my many interactions with Dr Adelman. I explained how I felt about my treatment at Lincoln to Professor Makris and asked him if he could be honest and straight with me at all times. Which he was.

26. I definitely have trust issues with medical professionals due to the contaminated Factor VIII that I was given and as a result of my interactions with Dr Adelman. Being constantly misled has affected my outlook and the way I have dealt and deal with things in life; this lack of trust has transferred to a lot of other areas in my life.

27. I then commenced a 12 month course of Interferon and Ribavirin towards the end of 1997/early 1998. I only managed to stay on the Ribavirin element of the course for a period of 4 months because it made me so poorly. I could not eat anything and it felt like I had a trap door attached to my stomach. It was extremely detrimental to my mental state and I therefore discontinued this element of the treatment. However, I did manage to sustain the full 12 month course in respect of the Interferon treatment. I successfully cleared Hepatitis C in 1999.

28. I did not confide in many people about my Hepatitis C although now I do not actively hide it, I freely tell people about my issues, it's been part of me and I'm certainly not ashamed about it. My family was very supportive from day one always there should they be of need. One or two friends I confided in, one or two friends disappeared as a result.

29. In terms of experiencing stigma I was relatively lucky in this regard although I do recall one incident one evening in or around 2002. I was out with friends and one woman, who was a prison officer, was also out with our group of friends on that evening. She treated me as if

she was sat with a leper and looked like she was going to jump out of her skin at any moment. She displayed a terrible overreaction to me. She apologised to me later when I subsequently bumped into her on another night out.

30. I struggled financially as a result of my Hepatitis C infection. I stopped working in 1995 and then managed to get back to work again in 2002. I have a very strong character and I refused to give up. However, I do feel that I am not now as strong as I once was, certainly mentally. Once back to work it took me a little while to get back into my chosen field of employment. The firm I left when poorly with the HCV infection took me back on. However for insurance purposes I did need to get a letter (from a Doctor) stipulating that I no longer had HCV and it wasn't likely to come back. This was because had the infection resurfaced they wouldn't have to pay me NFU insured sickness pay.

31. Despite my strong character, there have been times when my depression really took over. To be quite frank there are times when it would have been easier to die than to live and there certainly have been times over the past 25 years when I wanted to depart from this world. I don't think people truly understand the damage that Interferon does to the mind. This aspect is where I really struggled to confide in people. My Mum and dad I told around 2010 and I have confided in my partner of now. It must be hard to hear that you son/boyfriend finds it harder to live and would like to be gone. The guilt that come with that statement when so many of us have died and grasped at life causes anxieties also.

32. My memory and concentration are much poorer than they used to be following my Interferon treatments. I have been and am often still completely exhausted and fatigued. I don't know how I managed to do my job as a farm manager; which was both a complex and responsible role.

33. My fibromyalgia has recently worsened and now necessitates me taking tablets for the rest of my life. However, the tablets affect my liver so it is a catch twenty two situation.

34. I have osteoporosis in both hips which necessitated a left hip replacement operation in October 2017 and my right hip now also needs replacing. In fact the right hip is in a worse condition than the left one was in prior to the operation, although it causes me less pain.

35. My ankle joints are calcified and I can't walk very far anymore.

36. I am therefore limited both physically and mentally as a result of my infection with Hepatitis C.

Section 6. Treatment/Care/Support

37. I have noticed that I am treated slightly differently to non infected patients by medical professionals. They don't think I notice but I do and it is the little things that I notice. Medical professionals always glove up and act more cautiously and carefully around me.

38. I was never offered any counselling or psychological support when I was told that I had been infected with Hepatitis C in 1995.

39. Following my infection with Hepatitis C I suffered with depression. I have managed to deal with matters alone for a long time, which included taking anti-depressants at some points, but recently my own coping mechanisms started to fail. I do have a good support network around me and my girlfriend is fantastic but recently I have started to feel very low. I therefore reached out for help and have been enrolled onto a Cognitive Behavioural Therapy (CBT) course and I am taking anti-depressants whilst waiting for the CBT course to commence.

Section 7. Financial Assistance

40. I nearly missed out on the Stage One Payment from the Skipton Fund. It was Dr Makris who filled the paperwork in for me to receive the £20,000.

41. I had to drag up the past which I had buried away during the application process for the Special category Mechanism application procedure the process was very draining and to be quite honest they know what they have done and it should be given automatically.

42. I now receive the Special Category Mechanism (SCM) payments which commenced in or around February/March 2018. I was awarded £18,000 per annum. I also received some back pay and a winter fuel payment of £500 during the winter of 2018.

43. The staff at EIBSS are very good but the way in which we have to beg for money is disgusting. I am surprised that people have not committed suicide because the process is soul destroying; applicants need to disclose almost every aspect of their finances which are then examined with a fine-tooth comb.

Section 8. Other Issues/*Conclusion*

44. This tragedy has destroyed my life. I can remember that when I was a young man I laughed a lot and I was both funny and happy. The man who sits here today is nothing like the man who started out. This has affected me in a horrifically negative way. When a loved one dies we grieve the loss, how do you grieve about your lost self.

45. I found Collins Solicitors via writing to Jason Evans when I left the Haemophilia Society and GRO-D. I did not like GRO-D approach and wished them well with there future endeavours.

46. I do go on some of the Facebook support groups via my girlfriend's Facebook as I don't have my own page. Offer support and explain how certain things have affected me, mainly to help them realise they are not alone.

47. My Life is not a dress rehearsal for the main event this is the only life I have. I do want compensation for the person this scandal has irreparably damaged and would be extremely happy should people be prosecuted. Although I was "*cured*" of Hepatitis C in 1999, I was certainly not cured mentally or physically. Every day I wake up to deal with the after effects of Hepatitis C the fallout so to speak.

48. Learned people made catastrophic misjudgements, cutting corners to save a few pounds. Experimenting on people who looked up to doctors as protectors when life goes awry. However as page after page shows, they acted with impunity, never believing the notes would be read by patients. The saddest part of this scandal is the fact that every single politician who could have righted the wrong has avoided or buried the obvious. Its time a government stood tall, acted honourably and gave sensible reparation (compensation).

Anonymity, disclosure and redaction

49. I do not wish to apply for anonymity and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C ....DATE 08-05-19..........