Witness Name: Matthew Gregory
Statement No WITN1253001
Exhibits: WITN1253002
Dated:12th December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MATTHEW GREGORY

I, Matthew Gregory will say as follows:-

Section 1. Introduction

1. My name is Matthew Gregory. I was born on the GRO-C 1969 and live with my wife and stepdaughter at GRO-C GRO-C GRO-C. I am currently unemployed and receive Employment Support Allowance.

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 suffer from Haemophilia type A classed as severe. I was diagnosed with haemophilia whilst receiving medical treatment at the age of 2 years.

4. I was initially treated at Sheffield Children's Hospital, Western Bank, Sheffield until I was about 6 years old. Every time I had a bleed I would be transferred by ambulance to this Hospital, where I was treated with cryoprecipitate. When I was 6 or 7 years old, my treatment was transferred to the Derbyshire Royal Infirmary

(DRI) Hospital. In Derby I started being treated with Factor 8 products made by Kryobulin Lister AHG and Cutter Laboratories from about May 1976. I refer to Exhibit WITN125002.

5. I have seen from a letter in my medical records that I tested HIV positive on 30th September 1985. I am unsure of the exact date when I was infected. I was 16 when I was told I was infected. There was a brief discussion in the Doctors office between my doctor, myself and my parents, along the lines of 'this is what he has got and that's it'. The only advice received was "Don't have sex ". There is no record of this meeting in my medical records.

6. In my view the above meeting only took place as a result of my father having made many unsuccessful attempts to speak to the Doctor on the phone he, eventually managed to collar the Doctor on her ward rounds and pressured her into agreeing to a meeting to discuss his concerns over HIV . If this hadn't happened we wouldn't have been told about my infection. The Doctor was avoiding us.

7. I found out in 1991 (aged 22 years) about being infected with Hepatitis C. My doctor was Dr Angela McKernan. There are no notes in my medical records about this. From memory, I was aware from everything going on at the time i.e in the media about Hepatitis C that I was likely to be infected.

8. I was not given any information about how to manage being infected with Hepatitis C. I would have liked to have been given more information at the time. I feel that the news was given to me badly. I do not blame the doctors as they are not used to giving this sort of information to people. Haematologists do not deal with this sort of area. They are more academic and scientific. I am happy for doctors to treat me as a case.

9. It would have been nice to have been offered support from a nurse, perhaps pastoral care or counselling for the HIV As mentioned above the only advice received was "Don't have sex".

10. For Hepatitis C I was not given any information about the risks of transmitting to others.

Section 3. Other Infections

11. In or about September 2004 I received a letter from Dr McKernan informing me I had potentially been exposed to vCJD and telling me the Factor 8 Batches involved. I was told to inform all relevant medical professionals.

Section 4. Consent

12. I believe I have been tested without my knowledge or consent for HIV and Hepatitis C. My parents did not consent nor were they consulted.

13. I have no idea if any samples were taken for research. There is nothing in my medical records from what I have seen.

Section 5. Impact of the Infection

14. The physical effects of the HIV and Hepatitis C infections are difficult for me to determine precisely due to being a Haemophiliac. I consider the worst time was when I had the second round of Interferon as the side effects were horrendous. I also have also felt quite lethargic. I believe I would have done more if I had not been infected with HIV and Hepatitis C.

15. The biggest impact is never having children and being able to have a family. Also having to lie to people about my condition throughout my life and the constant worry someone might find out.

16. I have had peripheral neuropathy in my feet since I was about 16 or 17 years old. I have various cognitive difficulties, mainly because of my Hepatitis C infection/treatment. I am no longer able to concentrate for long periods of time or read. This has been one of the most irritating things as I used to read a lot. Now

when I start reading after about 5 minutes I lose concentration and I am unable to continue.

17. In 1996/7 I was treated with non Pegylated Interferon. I had this via 3 single injections a week. I didn't finish this course because I had a fire at my house and the treatment made me feel very unwell. I was not given any warnings about the side effects.

18. Until about early 1984 I was classed as a chronic non-progressor. In October 2003 I went to the DRI and had some blood tests. In January 2004 Dr McKernan phoned me and said 'there has been an anomaly in your test results can you come and see me'. She said "I am sorry these should have been picked up a couple of months ago". My CD 4 count which should be 800+ was 45 in October 2003 when the blood test was taken. Whilst I did feel ill. I didn't contract any horrific infections. I had started taking HIV medication. I was allergic to the AZT which I started on February 2004. Shortly after, I was put on Ribavirin and commenced Interferon treatment. Starting both at the same time was pretty stupid but necessary.

19. The treatment made me feel pretty rubbish. I had to take a prophylactic antibiotic to prevent me from getting chest infections which was horrible. I was given a warning about the side effects of the HIV medication. I saw a HIV doctor in Nottingham and he was very good and supportive. There was also a HIV specialist Pharmacist who was very helpful.

20. When I started the second round of treatment for the Hep C in 2004, other than a doctor telling me I could become depressed, I was not given any advice or warning as to the side effects. After 6 weeks of taking the medication I saw the doctor who said to the trainee who was with him "we have had a lot of problems with this treatment a number of people have killed themselves". The side effects were horrible. I slept for 17 hours a day and ate nutritional supplements for a

year. It did clear the Hepatitis C. The Hepatitis C nurses at Nottingham were very helpful.

21. Relationships have always been difficult. I used to work for the Terrence Higgins Trust and we used to give Blood Borne Virus Talks. We used to talk about disclosure. This is the most difficult thing, deciding when to tell a potential partner or friend or if to tell someone at all. I have always been very lucky as I have never had a bad reaction to telling someone about my condition. I believe this is due to coming from what I would describe as a middle class background; my peer group are intelligent, socially accepting people. The thought of infecting someone else is the most horrendous thing.

22. My family never discussed my condition. It was only spoken about if absolutely necessary. We avoided telling people by avoiding them. Generally it was better to lie. I didn't feel ostracised as I didn't give people the chance to do this to me. If people didn't need to know then I didn't tell them. I have two older brothers, they knew but we didn't discuss it.

23. Just after I was diagnosed with HIV I got peripheral neuropathy in my feet and Dr Mitchell said "it is the start of the end". Luckily, Gwyneth , the Haematologist nurse, said outside the room "I wouldn't worry too much about it" and this sort of reassured my mother.

24. The diagnosis of HIV and Hep C affected my parents' relationship. It has been a massive strain on them over the years. They have been incredible to cope with the strain all these years without it destroying them. I was a child when I was diagnosed with HIV. The affect on my mother was much worse. My dad is in the late stages of GRO-C at the moment but back then he knew so much about the problems.

25. I am lucky it doesn't cause a strain on my marriage, I believe this is because I am not stressed by my condition so it doesn't stress any one else out. I have found that younger generations are a lot more understanding and have not been programmed to fear HIV. The biggest effect has been on my sex life through the

years. It has made intimate relationships difficult. This has had a knock on effect on the quality of my relationships.

26. I believe my Infections affected my education. I was diagnosed just before I was going to take my O levels. I was told that I probably wouldn't live past 20. I was expected to go university but after the diagnosis I felt there was no point. About 50% of the pupils at my school went on to university and I would have been expected to go as well. The HIV destroyed what education I could have received. I left school at 17 and went to work in bars and nightclubs. I did this on and off for the next 10 years.

27. The financial effects were substantial. Due to my lack of education I was only able to find low paid jobs. In comparison my older brother, who I am similar to, is in a high powered job. I am currently unemployed. I am not unintelligent. I am perfectly capable and I wouldn't have had any difficulty with a career.

28. By the time I realised I wasn't going to die, I was in my mid 30's. However, by then the stress of any job would have probably killed me off. I believe the stress of my job as a graphic designer working 40 hours a week, together with just having had a relationship breakdown, contributed to me becoming ill in 2003.

29. My parents are the people who have been most affected. They feel responsible for the infection as I was only 16 years old when I was infected.

Section 6. Treatment/care/support

30. I was not given or offered any support for the HIV infection other then once when I was offered a session with a social worker. There was little information or support about HIV until mid 2000's.

31. With regards to the Hepatitis C, I received Interferon treatment twice and I didn't have to struggle to get the treatment. The people at the treatment center I went to were very supportive. Counselling was available.

Section 7. Financial Assistance

32. I received payments from The Macfarlane Trust and the MFET of £20,000 and £25,000.respectivley and a one off payment from the Skipton Fund of £26,000 in 2002/3.

33. I receive ongoing support from the Macfarlane Trust in the form of small monthly payments of £266 a month. This was changed after the Archer Inquiry in 2009. The MFET was reinstated and started paying regular monthly payments of about £1300 a month.

34. I also receive from the BSA a HIV payment of £18000 a year. I also receive £18000 a year from the SCM. I now receive a means tested top up as I am not working. Having to rely on benefits is not ideal.

35. It has always been an embarrassing process applying for financial assistance. I have been a member of the Macfarlane Trust for the last 8 years. I know the staff and Trustees did the absolute best they could. The Macfarlane Trust had a social worker and she and the other staff helped me filling out the application forms.

36. When I was ill because of the Hepatitis C treatment, my benefits were stopped as I was deemed fit for work. I called the Macfarlane Trust in floods of tears and they helped me. There are application forms for everything. The process for applying for financial assistance is very lengthy. I found out that I was eligible for financial assistance by receiving letters from them. I believe these letters were sent to everyone who was infected. The system itself was shocking and should have never been designed in that way that it was.

37. BSA now want you to apply to the Mobility Charity before applying to them. I did not like this as I would have to disclose my HIV/Hep C status to them. BSA are now means tested, you have to jump through hoops just to get £500. You also have to provide bank statements. They are fairly new and not very consistent. This is very frustrating. I shouldn't be in a position where I have to go and do this.

38. The pre conditions for financial assistance are based on need and income - it is all means tested it also depends on whether the trust have got any money.

39. The Trust system is an ill conceived system but the staff and the Trustees have always worked with the best intentions within the restrictions which they have. The people who have been hardest done by are the widows and the bereaved. They have had so little support and this should never have been the case.

Anonymity, disclosure and redaction

40. 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. I would like 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 ....

Dated ..12.12.18.. GRO-C ....

Medical Chronology

(This summary is not exhaustive but sets out key points in the records relevant to the statement)

09/01/1970	Diagnosed with Haemophilia
28/04/1977	Diagnosed as Australian antigen positive
00/00/1985	Diagnosed with HIV
00/00/1991	Diagnosed with HCV
28/11/1997	Letter about theoretical risk of transmission of vCJD