Witness Name: Michael John Gower
Statement No: WITN1748001
Exhibits: 0
Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MICHAEL JOHN GOWER

I, Michael John Gower, will say as follows:-

Section 1. Introduction

1. My name is Michael John Gower. I was born on GRO-C 1945 and I live at GRO-C GRO-C London, GRO-C

2. I am married and I live with my wife, Heather Gower who has also produced a witness statement for the Inquiry (**WITN1659001**). We have a daughter together, Joanna Victoria Gower who is my main carer and also produced a witness statement for the Inquiry (**WITN1658001**).

3. I have 10 siblings (6 sisters and 4 brothers). Two of my brothers died of Haemophilia. GRO-C

4. 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

5. I suffer from severe Haemophilia A and my clotting factor is 1%. I was diagnosed with Haemophilia in 1946 at the age of 1 following a bleed after biting my lip. The doctors already knew that Haemophilia ran in my family as 2 of my brothers had died from it.

6. I was initially given Cryoprecipitate and from the mid/late 1970s I started receiving Factor VIII (FVIII) treatment. I was not given any information about FVIII and why they changed my treatment from Cryoprecipitate to FVIII except it was better for me.

7. I require FVIII treatment as and when I have a bleed. I used to administer it myself, but I am unable to do so now because my arms and joints are too painful. Now, my wife, Heather administers FVIII to me as and when I require it.

8. I do not believe I was provided with any information or advice beforehand about the risk of being exposed to infection whilst using FVIII. Had this information been provided before they switched my treatment I would have thought twice before taking it.

9. I believe I was infected with Hepatitis B (Hep B), Hepatitis C (Hep C) and HIV at the Royal London Hospital where I was treated by Dr Brian Colvin. I am now under the care of Professor Pasi and Dr Hart as I believe that Dr Colvin has retired.

10. I was told that I was infected with Hep B following a knee surgery 1977. I came home after the surgery and a few weeks later, I became ill and I was jaundiced. When I went to the hospital I was told I had Hep B and was barrier nursed for about three weeks. I recovered and I was told that I was better.

11. In 1985, I found out in a terrible way that I was infected with HIV. At the beginning of 1985, I was told by Dr Colvin that I was infected with HTLV-III (previous name for HIV) but I was never told what it meant. I did not know it

was to do with AIDS. Dr Colvin said HTLV-III was a similar infection to Hep B and so I did not know how serious it was at the time.

12. In or about October 1985, after I was told that I was HTLV-III positive, I went into hospital for an elbow operation. I was immediately put into a private room. At this time I did not know what was going on. The nurse came into the room covered head-to-toe and asked me how long I had had AIDS. At this point I was completely shocked because it was the first time that I found out that I had been infected. I heard the doctors and nurses talking about me in the hallway, shouting about why I was told that I had AIDS. I asked Dr Colvin about this and he had a go at the nurse for blurting it out. He later apologised to me about it. Heather and I were both completely in shock and it went over our heads.

13. I was told at a later appointment that I had a 6 month life expectancy. I did not know how to react to what I was told, it just shocked me. No other information was provided to me about HIV. We started to hear more about it through the media.

14. In the 1990s, I was told that I needed to be tested for Hep C and given leaflets regarding it. I was confused as to what was going on. After the test, I saw a liver specialist who told me that I had tested positive for Hep C. I was not provided with much information about Hep C other than the leaflets that were given to me. I knew that Hep B was an acute illness and it had a few side effects, but it was not explained to me that Hep C was much more serious. We were all more concerned about HIV at the time as everyone knew what it was back then and it was portrayed as a deadly disease by the media.

15. By the time I was provided with information about Hep C, the damage had already been done to my liver. I was just given general information and advice relating to liver disease such as not to drink alcohol.

16. I believe that information about HIV should have been provided to me earlier as it was an awful time for us all. I would have liked to be given information

earlier about Hep B and Hep C but I do not know if it would have made any difference.

17. Prior to my marriage in 1979, I told Heather about the Hep B infection. I was not provided any information about the risk of infecting others with Hep B or HIV, but I knew from the doctors' and the nurses' attitudes that HIV was a very serious infection. We got most of our information from the media. I knew Hep C could be transmitted as Heather was asked to have a Hep C test, which she did. This was the first time that I found about that Hep C could be transmitted.

18. My daughter was not tested for HIV as a baby and no one advised us that she should be tested. I do not know if she was tested when she was older but I believe the doctors knew that there was a risk of me transmitting the infection to her and so they should have told me.

Section 3. Other Infections

19. As a result of the infections, I now suffer with a distorted/deformed knee and foot leading to poor mobility. I have to walk on my tip toes. I was told it was too difficult to be operated on because there is a high risk of further infections/complications. I also suffer from insomnia, depression, and skin complaints. Between 1982 and 1985, I had my teeth removed, hip replaced and had an eye injury which led to hospitalisation and increased FVIII treatment. In 2015, I had a diverticulitis and treatment was delayed until my condition became life threatening and I now have a stoma. I feel I would have had a better outcome without all the complications related to the infections.

20. In the early 2000s, we received a letter stating that I could be at risk of having vCJD. The letter stated that it was a possible that I had been given contaminated FVIII blood products which had included donations from someone infected by vCJD. The main complication this causes is the way I am treated for invasive procedures. I am supposed to disclose this to any medical personnel treating me. I am never treated promptly and often get moved off surgical lists if emergency cases come in. I know that vCJD can

only be diagnosed after death and there is no treatment for it and so this uncertainty has caused so many mental problems over the years. I cannot even apply to the vCJD compensation fund as I cannot prove I have the infection even though I am treated as if I have it.

Section 4. Consent

21. I believe there was a possibility that I was treated and tested without my knowledge.

22. I did not give my consent to be tested for HIV. I was just told that I had HTLV-III, which was not explained to me. I only found out that it was HIV positive when I went in for my elbow operation and the nurse blurted it out.

23. I was definitely not provided with adequate or full information about the test results and I believe I was definitely treated and tested for the purposes of research.

Section 5. Impact of the Infection

24. I have suffered mental effects as a result of the infections. I used to get worked up and stressed all the time. I also used to get hot sweats. It shook me at the time when I found out I had the above infections. My initially thoughts were that I was not going to be around for long especially after being told that I had 6 months to live. I wanted to make the most of my time left. Knowing that I had HIV, I was constantly worried about the uncertainty of what could happen to me and when it would happen to me.

25. I also suffered physical effects as a result of the infections. I had jaundice twice and that shook me up. No one told me how serious the infections were. I was very weak all the time and was unable to relate the symptoms to the infections.

26. I believe I have also suffered further medical complications as a result of the infections. Whenever I had a medical procedure, I was always the last to have it. Sometimes they would cancel the appointment on the day and

reschedule it for another day. I now suffer from arthritis in most of my joints. I had one knee removed and the another knee is distorted. I now need a wheelchair. I also have permanent stoma after diverticulitis caused blockages. I have liver damage as a result of Hep C and am currently on a liver transplant list. I have untreated depression and insomnia.

27. I was offered AZT treatment for HIV soon after I was told that I had HIV. However, I initially refused to take it as I did not want to use drugs that had not been tested and that had not been proven to work. I also heard horror stories in relation to the side effects that the treatment had. However, in the late 1990s, I was getting quite poorly and I was told it was time to take the Antiviral combination therapy. I am now taking 3 tablets every morning.

28. In the mid 1990s, I was put on a 6 month trial for Interferon treatment for the Hep C infection but I did not feel any significant changes. Unfortunately the treatment did not clear the Hep C. In or about 2015, I had a second course of treatment called Harvoni which finally cleared the Hep C.

29. I do not know whether there were any other treatments which I consider ought to have been made available to me at the time.

30. I was not comfortable having so many injections as they were quite intrusive and painful.

31. I believe my infected status impacted on the medical treatment I received. As previously stated above, I was always at the bottom of the list or the procedure would be rescheduled for another day. I was treated very badly whenever I had operations at hospital. Once, I had a haemorrhage in my elbow but the nurses would not call a doctor to treat me for it. When they did come, it was too late and they had to reopen my wound and operate. Dr Colvin apologised profusely. In 1985 when I was in hospital for my elbow operation, my family would come to visit as they always had before, and they noticed a sign on the door stating 'do not enter, AIDS patient'. That was really upsetting. Not only did my family see the sign but the sign was there for the public to view and everybody knew I was infected with the AIDS virus.

32. The infections also had an impact on my private, family and social life. In the early days, my family would not come near me. One of my sisters went home GRO-C GRO-C Another sister GRO-C GRO-C I am now only close to two of my sisters. Most of the other family members did not want to know me anymore. I recall an incident when I received £60,000 from the Macfarlane Trust that one of my brothers GRO-C made a comment saying 'oh you could go and buy a car now with that money' as if I had won the lottery. I do not believe he understood how much being infected affected me. The whole situation was very stressful.

33. My daughter was only 4 years old when she worked it out for herself that I had HIV. She was watching TV one day when an advertisement about AIDS came up. She just looked at it and asked my wife whether I had AIDS. My wife did not keep it a secret as she did not want to lie to our daughter and told her everything. I believe my daughter found it difficult as she had to keep it a secret and was unable to tell anyone as they would not understand how I got the infections because of the way the media portrayed it.

34. The infections affected my employment. From 1969 I worked in the x-ray department at Whipps Cross Hospital. I got on very well with my colleagues and I really enjoyed my job. Working there I met my wife, we even had our wedding reception there, free of charge as a present from the hospital. Following my elbow operation, I returned to work in 1986. As soon as I returned to work, the hospital moved me out of the Main and A&E x-ray departments and into the Chest Clinic, which was a separate building away from the main hospital. I was working alone, as the radiographer and patients were kept away from me with the only contact through a lightproof hatch. I was mentally affected as I was very sociable and did not like to work alone. It really upset me that they moved me because of my infected status. I did try and work but was unable to cope with the isolation and asked to be moved. The alternative tasks offered were too much for my disability and therefore I was offered retirement on medical grounds which I took up. This therefore

had a financial effect on me. I would have loved to continue to work as I really enjoyed my job.

35. There was definitely a huge stigma attached to the HIV at the time. Whenever people used to say nasty things about HIV, I used to educate them and give them pep talks about it. I blame the media for portraying it in such a bad way.

36. In the 1990s I joined a local support group for people with HIV/AIDS. I believe we received a letter inviting us to join. It did helped knowing that I was able to talk to people who were in a similar situation.

Section 6. Treatment/care/support

37. I did not face any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected apart from those already referred to.

38. I was not offered any counselling or psychological support as a consequence of being infected. If I was offered it, it may have helped me. My wife and my daughter keep me going.

Section 7. Financial Assistance

39. In the early 1990s, I received a payment from the Macfarlane Trust. I cannot remember how much I received. In the late 1990s, I received a second payment of £60,000 from the Macfarlane Trust but was asked to sign a waiver to confirm that I would not make any future claims.

40. I also received a Stage 1 lump sum payment of £20,000 from the Skipton Fund but I cannot remember when I received it.

41. The process of applying for both the Macfarlane Trust and Skipton Fund were straightforward other than fact that they required quite a lot of information from us.

42. I receive monthly payments from the EIBSS of just over £2,000 each month (£1,000 each from the Macfarlane Trust and Skipton Fund) from when they first started. I also receive a winter fuel allowance every year.

43. A while ago, I wanted a mobility scooter but was required to show proof that I needed it. I was required to get reports from consultants to prove that it was a necessity for me. It was a hassle to apply for it and to go and see them. It was quite intrusive. My daughter also applied for a reclining chair for me, which was difficult to start with, but I eventually got it.

44. The staff working for the Trusts and Funds are very intrusive and I do not want to have to speak to them each time I need something. Further information is always required by the Trust and Funds which delays payment.

Section 8. Other Issues

45. I want justice and answers for the people who died as well as those that are still alive, infected and affected, as it has been going on for far too long.

46. I lost so many friends over this scandal that have passed away which makes me very teary and upset. I have survivors' guilt and it makes me very emotional to think that people who were younger than me who were infected are now dead. It is impossible to get my head round it.

47. We wanted another child but because I was infected, we lost our chance to do so.

Anonymity, disclosure and redaction

48. 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.

49. 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

Dated 28/03/19