Witness Name: Melanie Claire McKay
Statement No: WITN3587001
Exhibits: 0
Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MELANIE CLAIRE MCKAY

I, Melanie Claire McKay, will say as follows:-

Section 1. Introduction

1. My name is Melanie Claire McKay. My date of birth is GRO-C 1978. I live alone at GRO-C. I do not work due to my medical conditions.

2. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

3. I was born six weeks premature in Karachi, Pakistan, along with my twin sister. Our mother did not know that she was having twins until five hours before she gave birth. As soon as I was born, it was apparent that something was wrong with me and I was referred to as the "blue baby." We lived with our parents and older brother at the time.

4. We moved to the UK a few months later in February 1979 and lived with my grandparents in GRO-C Surrey. A few years later we moved to Sheffield,

where I was diagnosed with a genetic condition called Noonan Syndrome. This prevents normal development leading to various health problems, including problems with hearing, eyesight, skeleton and heart. In my case, it included pulmonary valve stenosis (a condition leading to obstruction to blood flow from the right ventricle to the pulmonary artery), short stature, hearing loss, hypermobility, resulting in my joints moving significantly beyond the normal range, poor eyesight and mild to moderate learning disabilities. I also had a hole in my heart.

5. In February 1983, at the age of four, I underwent open heart surgery. I was under the care of Dr Magdi Yacoub in the cardiology department at the Royal Brompton Hospital. During the surgery I was given a number of blood transfusions. It was later confirmed that a staff member also donated blood, without my mother being made aware. Later on that year on GRO-C 1983, my younger brother was born.

6. In August 1984, at the age of five, I underwent a tonsillectomy at the Royal National Throat, Nose and Ear Hospital (University London College Hospitals). It was a very complicated procedure where I suffered a haemorrhage and was returned to theatre. I was then discharged and within a week was rushed back into hospital due to further haemorrhaging. My parents were then told by a consultant (I do not recall their name) that I would die unless I had Factor VIII concentrate injections. They were not informed of any potential risks associated with it. They later denied administering Factor VIII concentrate and claimed this would have been given to me by the Royal Brompton Hospital instead.

7. I moved back to Sheffield in 1985 and was under the care of many different paediatricians and doctors, as I suffered from problems with my joints and my hearing.

8. In 1987, I was referred to the Haematology clinic at Sheffield Children's Hospital by the orthopaedic surgeon, Dr Smith, at Rygate Centre. I was also referred to Professor Lillyman at Sheffield Children's Hospital, due to the

haemorrhage I suffered previously. There was a question as to whether I had bleeding tendencies.

9. Since I was only nine years old at the time, any correspondence regarding my health went straight to my parents. My parents received a letter on 16 December 1987 from Professor Lillyman stating that I was not suffering from any bleeding disorders or had bleeding tendencies, but that they had found another problem. I was confirmed to be Human Immunodeficiency Virus (HIV) positive. There was no mention of when I contracted it. Professor Lillyman was trying to find the contaminated batch numbers, but was not able to provide us with any further information. My parents were then told that their daughter would not live beyond the age of 10.

10. I am not aware as to whether my parents were specifically informed about the risk of transmission to other people. However I do believe they were aware as to how it is transmitted. I recall having to keep a blue wicker basket for my towels and toiletries.

11. GRO-C

12. My consultant contacted the blood transfusion department, to try to figure out where the HIV might have come from and in particular the batch numbers used. He managed to obtain some batch numbers, but some blood components were not recorded on patients' records.

13. I was not told about my status until 23 August 1994, when I was 15 years old. My mother, stepfather and biological father all came with me to Sheffield Children's Hospital. My biological father would not allow my stepfather into the meeting as he said it had nothing to do with him. My consultant at the time, Dr Katy Forman, sat me down and said that when I was a baby and I had surgery, something went wrong and I was infected with something called HIV. Although I had received a few transfusions, they were not sure which transfusion specifically caused me to be infected.

14. I burst into tears and could not believe it; I even said "you're lying to me." I did not know what HIV was at the time or how it affected me. Dr Forman gave me a pen and notepad and told me to write down any questions I had. She said that I did not have to book an appointment and that I could just come into the ward and she would go through it all with me.

15. I recall my father wanted to take me out for lunch after the appointment, but I didn't want to go. I went with my mother and stepfather instead to Pizza Hut. Whilst there, my stepfather asked me if he could tell his sergeant and inspector at work, so that whenever I needed to be taken to medical appointments, he could be there for me. His colleagues were very supportive and allowed him to drop everything and come to my help whenever needed.

16. A few weeks later, I returned to have another consultation with Dr Forman. She had received my notes and tried to answer the questions I had, explaining everything in a way that I could understand. She explained what the CD4 count was and how it affected my blood, as well as what the AZT treatment and Septrin were for. I was later transferred to the care of Dr Adam Finn.

17. When I was first told about my status I was upset and angry that I was not told before. My parents thought that they knew me better and that they should wait before they told me. At that point, my twin sister, older brother and teachers at my secondary school already knew. They were all scared about how I was going to take the news.

Section 3. Other Infections

18. I am not aware that I contracted any other infections as a result of receiving contaminated blood products.

Section 4. Consent

19. As I was a child, my parents would have had to have consented to testing. However, I do not believe that they were informed about the specific tests taking place, as even they were shocked to find out that I had HIV.

20. In the medical records I have managed to obtain, I found I was also tested for the Hepatitis C virus at the same time, but my parents were never informed about this either. Thankfully, this test came back negative.

21. I am not sure whether I was ever treated or tested for research purposes.

Section 5. Impact of the Infection

22. When I was first told about my infection I was upset, angry and I wished I was dead. I wanted to kill the person that did this to me. I often asked, why me? Why has this happened to me? Once I was told, I made the decision that I would tell my nine year old brother, because I felt he should be told what was wrong with his sister. I felt like my whole life came crumbling down.

23. When my parents first found out about my HIV infection they were shocked and horrified. I had to have all my toiletries and towels in a separate basket and separate from the rest of the family.

24. My health had always been a roller-coaster because of Noonan Syndrome but it further deteriorated as a result of HIV. I repeatedly had chest infections and colds and in 1990 I was put on Septrin on a prophylactic-basis to prevent Pneumocystis Pneumonia (PCP). I was constantly in and out of the hospital.

25. I was not put on any treatment at the beginning. I had medical checks to see how the virus was progressing. In 1989, when I was 11 years old, I was put on Azidothymidine (AZT), which was the first treatment available to manage HIV. It was given to adults more so than to children, but I was still put on quite a high dosage. I recall it being awful and made everything taste horrible.

26. AZT also made my platelet count drop very low, which meant I had to have regular blood transfusions. Eventually, they had to alter the dosage of the drug to make it more manageable and easier for my body to tolerate.

27. HIV heavily affected how I was treated at school. Everybody around me had to be very careful. I remember once I fell over and when another pupil tried to help me up, a teacher shouted to them: "don't touch her". This was before I was told about my infection, so I found it strange, but it also made me realise that something was most definitely wrong with me.

28. Growing up I thought that I had cancer. Whenever I had an appointment at the clinic, I was always put amongst children who had cancer. I really believed that I had some form of cancer where I did not lose my hair.

29. In 1994/5 I attended a mainstream secondary school and after I was told about my HIV status, I spoke in length with my head teacher. Everything appeared fine from the school's side of things; the school was told about my infection and were well informed about my educational needs. There were no issues. I was told that they would get any relevant training that they needed.

30. However, one day I went to school and my mother turned up and dragged me out saying that I couldn't go there anymore. She did not think that it was suitable for me to go to a mainstream school anymore, despite the fact that the school were happy to have me there. My stepfather was always very supportive and encouraged what I wanted to achieve, whereas my mother was over-protective, given my medical history. I was doing very well in Maths, English and History, but I never managed to finish and obtain my GCSEs.

31. I suffered with bad headaches and had numerous blood tests, which all came back inconclusive. CT scans and MRI scans were also performed, but nothing showed up. At that point, the headaches were quite intense and started to affect my performance at school. I was put on dihydrocodeine and paracetamol.

32. I eventually had a lumbar puncture, which showed that my intracranial pressure was too high, so I was drained of some cerebrospinal fluid. This helped, but not for long, so I had to repeat this process several times.

33. Whilst under the care of Dr Chris Ritty, a neurologist at The Ryegate Children's Centre in Sheffield, it was decided that I should have a shunt put in. I couldn't have a normal shunt, as the risk of a post-operative infection was too high, due to my infected status. My surgeon, Dr McKinnon, put in a peritoneal lumbar shunt instead. This was in March 1995 and finally cured me of my headaches.

34. In 1995, I was transferred to the Hallamshire Hospital, where I was cared for by Dr McKendric and his team at the Infectious Diseases and Tropical Medicine department. They changed the combination of my treatment and put me on Didanosine (DDI) and Zalcitabine (DDC). I suffered from great side-effects, which included headaches, backaches, nausea and diarrhoea. I was admitted to the ward and further tests were done before they stopped this combination and tried others. However I still suffered from diarrhoea, vomiting and headaches.

35. In summer 1998, I was rushed to Hallamshire Hospital with severe headaches and vomiting. After several days of tests I was diagnosed with viral meningitis and another form of meningitis. My mother was told by my consultant, Rob Read, that my brother needed to come back from Belfast, where he was based with the Scouts Guards at the time. I was totally unaware of how poorly I was or what was going on around me. They eventually managed to handle the infection, but I continued to be in ill health. I also had to have my shunt removed, because it had got infected too. I was then finally discharged in October 1998, just before my 20th birthday.

36. It is very possible that all those infections could have been caused by my weakened immune system and the fact that I did not have a suitable treatment plan to manage HIV and limit its effects.

37. In 2004, I was given heart medication as I was told my heart was failing. I was advised to be on bed rest for a month whilst in hospital.

38. A friend from Shield HIV Support, which is an organisation that provides support for people with HIV, gave me an article from Gay Times magazine for a respite centre in Bridlington. When I contacted them, I spoke with Jo Stephenson at the therapy centre and began to attend regularly. The staff would have to put me on the train home, because I never wanted to leave. I always felt great after going there.

39. In 2007, my mother's health began to decline and as such, she could no longer be my primary carer. With the help from the Eileen Trust and Jo Stephenson, I moved to the Therapy Centre to learn the life skills needed to live independently.

40. In 2008, I was admitted to Hallamshire Hospital with a horrible chest infection. I was still on Septrin and out of nowhere I got a rash, my tongue started to get numb, I had itchy eyes and I generally felt strange. They then stopped Septrin and prescribed Nebulised Pentamidine once a month. It gave me such a high temperature that I had to be admitted to the hospital again. Eventually I was going to hospital every month for treatment, but would not need to be admitted.

41. In 2010 I suffered from an asthma attack and was given an inhaler. Unfortunately, it quickly became apparent that my asthma inhaler interacted with my HIV treatment, so I had to be put on steroids instead, which I have been taking ever since.

42. In 2016 I suffered from severe haemorrhoids, which in turn caused severe anaemia. I also became jaundiced and was admitted to the Royal Hallamshire Hospital in January. It was found that my haemoglobin levels had dropped to 7.9, so I had to have blood transfusion, after which my entire body was aching. The doctors thought things would improve after the transfusion but they didn't.

43. I was told that I might have another possible infection on my heart too and so they ran further tests to rule that out. The inhaler that my GP prescribed two years prior was called Seretied and even though I questioned its' interaction with my HIV medication; I was told it would be fine.

44. I was then diagnosed with adrenal insufficiency as I had a cortisol level of four and so was put on hydrocortisone. My heart then went into atrial fibrillation for which I was given Bisoprolol to try and reduce my heart rate. This didn't work and I was too close to the 48 hour cut off period to undertake cardioversion, so I was given daily injections for four weeks to prevent blood clots. I was transferred to the Northern General Hospital where the HIV team visited twice weekly and advised that my pulmonary valve was starting to fail.

45. Since the beginning of this year, I had not been feeling very well and my health started to decline. In July 2019, I had to call 111 as I had a high temperature and was suffering from abdominal pain, nausea and extreme fatigue. I was taken to Hull Royal Infirmary and was seen to by one of the HIV consultants, Dr Patrick Lilly, who I used to see in Sheffield. Dr Lilly transferred me to Castle Hill Hospital in their HIV ward where they carried out a number of investigations, including blood tests, a MRI and CT scan and an echocardiogram.

46. My CD4 count has dropped considerably since September 2018; it went from 148 to 108 in January 2019 and now down to 82, which now makes me more susceptible to infections and colds. Therefore, it has been decided that I have to be put back on prophylaxis treatment (Dapsone) to prevent PCP. They are also watching closely to see if I develop any rashes. I did not develop a rash but I did get widespread itching from head to toe and so Dapsone was then stopped two days later. I did however suffer from regular oral thrush, which was treated September whilst in hospital.

47. I recently applied for access to my full medical records from University College London Hospital and Royal Brompton Harefield Hospital, but was told that they had been destroyed a few years ago.

48. Over the last few weeks, my health has gradually gone downhill and I have been suffering with extreme fatigue. I was sleeping ten hours at night and around two to four hours during the day, and even then I was still very tired. I have no energy, suffer from headaches and high temperatures which would not go down. The doctors were worried that due to my being HIV positive and having adrenal insufficiency, I could develop more infections.

49. When I was younger my family and I experienced a lot of stigma as a result of my infection. A lot of people would not come to my birthday parties, because their parents were worried that they would catch HIV from me. My mum's friends were also too scared to come to our home.

50. My parents also found it very challenging to comprehend and deal with the fact that their daughter was infected with HIV. I think my mother handled it much better than my father. My biological father still cannot accept it and so I do not have a good relationship with him.

Section 6. Treatment/care/support

51. When I was around 16/17 years old I was given a specialist HIV social worker. I also had a Buddy, which was a system whereby a person came to the house and provided support, including counselling.

52. Due to the complexity of my health conditions and living with HIV I could not manage without a social worker. I need the support from staff when attending hospital appointments in Sheffield and Leeds. I approached Bridlington Therapy Centre to apply for a care package and was allocated social worker, Jo Stephenson.

53. I found the support very helpful and now during my hospital visits, I am less anxious and less stressed out. I normally get scared in new surroundings and sometimes I feel like I am not being listened to without Jo and the rest of the team.

54. Jo and the team have been supporting me for the last 12 years, and they have seen how much I have grown in confidence. They have worked with people with HIV for over 20 years and I know that without their care package I would not manage.

Section 7. Financial Assistance

55. All the benefits I was entitled to used to be addressed to my mother, so she used to receive all of my payments.

56. I was registered with the Eileen Trust and received a lump sum payment of £41,000. However, I did not see much of that money, as my mother spent it on holidays for us, along with an extension in the house so that I was able to have my own bathroom.

57. The Eileen Trust also helped me to move houses and helped to pay for a life skills course, where I learned to cook, budget and live independently.

58. I now receive £2,130 every month from EIBSS.

59. The process of obtaining the payments was relatively easy.

60. My benefits have now been changed to my name.

Section 8. Other Issues

61. I would like for the Inquiry to get to the bottom of this and find out exactly what happened. I would also like to know why the Government took so long to acknowledge the problem, particularly when they knew there was one in the first place.

62. I am hoping that there will be some sort of national compensation package. I think it would give us the closure we need for this NHS disaster.

63. The only way I keep up to date with what is happening, is by being part of the Tainted Blood Campaign. I have been a part of this for the last 15/20 years.

Anonymity, disclosure and redaction

64. 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.

65. I do 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 ....

Dated...10-9-19............................