

Witness Name: Michael Mason

Statement No: WITN1377001

Exhibits: WITN1377002-5

Dated: April 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF MICHAEL MASON

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I, Michael Mason will say as follows:-

#### Section 1. Introduction

1. I was born on the GRO-C 1967 and currently live with my wife Caroline Mason and our two daughters, Natalie and Nicole. I live at GRO-C GRO-C Leicestershire GRO-C. We have two cats and a dog. I am currently employed as Chief Executive of a charity.
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.
3. Where dates are referred to in this statement and I have not had access to my medical records those dates are recorded to the best of my knowledge given the passage of time.

## **Section 2. How infected**

4. I have severe haemophilia A which was discovered when I was 18 months old. Haemophilia has had a huge affect on my life. A third of my childhood was spent in hospital mostly with bleeds to my knee. When I was older my two ankles caused me issues and I was in hospital at least twice a month with bleeds.
5. When I was about 9 or 10 years old I moved from Cryoprecipitate treatment to Factor VIII concentrate. I learnt within a couple of weeks how to administer it myself. I attach as Exhibit WITN1377002 a copy of the Factor VIII treatment I received between 1980 and 1987.
6. In 1985, when I was 18, I was told that I was infected with HIV. I had been sent a diet sheet from the hospital which explained this is what you eat if you have HIV or AIDS. I didn't know why I had been sent it. I phoned up my consultant and got through to one of the nurses but she said she couldn't speak to me on the phone. I went to my GP and asked him if he knew anything about the diet sheet and why I had been sent it. My GP said he had known that I had been HIV positive for 18 months. It was a 2 minute conversation and one that I will never forget. He told me that he was not sure how long I had left but to go away, have fun but told me not to have sex. He insisted that they had told me when I was 16 but they did not; it is not something you would forget.
7. I was not given any information on how to manage the situation. I just left the room and went home. It just seemed like the doctors didn't know what to do. I was literally told not to have sex. I was not given any information about passing on the infection.
8. I believe the way I was told was morally wrong. I should have been told about the infection as soon as the doctors knew about it. It was negligent that they

didn't tell me as soon as they were aware. I was 18 and I was just told I didn't have long to live. I didn't have any support at all. [REDACTED] GRO-C

[REDACTED] GRO-C I didn't tell my dad about the infection for roughly 2 years.

9. In or about 1992 I was told I had Hepatitis C. From memory I think I received a letter that told me I may be at risk of having Hepatitis C. I went to the doctors and was tested by Dr Hill at the Queen Elizabeth Hospital, Birmingham (QEH). He confirmed that I was infected with Hepatitis C. At that point I wasn't told about the severity of the Hepatitis C. It is only over the years that I have found out how serious it could be.

### **Section 3. Other Infections**

10. I have been told that I am at risk of variant CJD. I got a letter about the risk of vCJD on 1<sup>st</sup> January 2000 [REDACTED] GRO-C. A copy of this letter is attached as Exhibit WITN137703. I received a further letter from my treating consultant at the end of January and a copy of this letter is attached as Exhibit WITN1377004. I was so angry that I stopped all my treatment. I rang the press and went on a treatment strike for my haemophilia; it was reported in the papers. It was awful that I had to do that. I was on the heat treatment at the time but it forced my local authority to give me the new, synthetic treatment. It took a few months until I was able to get the new treatment.

### **Section 4. Consent**

11. I believe I was tested without my knowledge. I was never told that I was being tested for HIV. In my records I have seen details of a test that was dated 1983 and that is how I know that my blood was taken and tested back then.

12. I believe that the professionals knew there was a risk of infection from blood products.

13. In 1983 the haematology department advised my GP that I had no history of hepatitis. In May 1985 I was informed that I had Hepatitis B. Copies of this correspondence are attached as Exhibit WITN1377005..

### **Section 5. Impact of the Infection**

14. In terms of physical effects of my Hepatitis C I suffer from fatigue and neuropathy.

15. I received Interferon treatment for Hepatitis C in 1994. It was hell and it changed me into a very different person. The side effects from the treatment included depression and I felt very fatigued. My personality also changed and my wife said I was like a completely different person. I thought I was fine but no one else saw that. I only had the treatment for 19 weeks. The side effects were so bad I had to stop. I had no strength in my hands and physically I couldn't do anything when I was going through this treatment. I was continuously ill and suffered from diarrhoea. At the time I was on 24 tablets a day.

16. In 2016 I was given Ribavirin which was the new treatment to clear Hepatitis C. I had to take one tablet a day and after 14 weeks the Hepatitis C had cleared. It took a long time for me to be given Ribavirin; I had to fight for the treatment. The worst side effect was fatigue which made me feel awful.

17. The mental affects have also been daunting. For the first few years I just ignored the fact I had the infections and went to work and spent time in the pub. I got myself into debt and I didn't care as I believed I was going to die and therefore wouldn't have to pay it back. I smoked and drank a lot. When I didn't die I had to start about thinking about paying my debts off and how I would do it. I did not have any intimate relationships as I believed there was no point. I also never applied for a mortgage.

18. I was 17 when I decided to become a Mortician. I had been working for about 18 months in the mortuary when I found out I had HIV. I wanted to be a Post Mortem Technician. However, they would have had access to my medical records and when they saw them I knew that they would not take me on. I lost my career due to being infected. Looking back I do not believe they should have had access to my medical records. After this I went for a job at the hospital where my father worked in Sully Oak but they wouldn't take me on because of my medical condition.
19. Being infected has affected my employment. In particular the side effects of my Hepatitis C treatment made me so tired that I physically couldn't work. There have been a number of years where I have kind of just drifted into dead end jobs.
20. My wife was told about my infection quite early on and she knew before we started dating. Fortunately, this did not affect our relationship and we became engaged. When I told the hospital I was engaged, they told me I only had two years to live so I should enjoy it. We married in 1990. When I got married I kept myself to myself. It is hard to make friends when you are keeping a large part of your life secret. We were always made to believe that we would never have children. We couldn't have unprotected sex ever and so we decided that we wouldn't have kids. Every birthday and Christmas we believed could be my last. I was constantly living my life around my CD4 count. In the house we talked about the infections openly but outside in public I always had to consciously watch what I was saying.
21. During the late 1990's, we heard via other people with haemophilia that the Queen Elizabeth Hospital in Birmingham was seeking to offer a specialist IVF pilot scheme for sero-discordant couples. We contacted the Haemophilia consultant and went through fertility tests. The tests revealed that there was an issue with my mitochondrial function in my sperm and that we would not be suitable candidates for the pilot. The consultant advised us that this was a

direct result of my HIV medication. After delivering this absolutely devastating news the consultant Johnathan Wilde, in a misguided attempt to make us feel better said "kid's aren't that great you know; one of mine decided to upend their cereal bowl all over me this morning". He showed a complete lack of empathy for our situation. I realise that it has affected me deeply as I remember it so clearly.

22. We did try IVF for many years. We got the money for it and found out there was a sperm washing facility so we paid for that. The NHS did pay for one cycle which cost £15,000 but we paid for the rest. My wife just didn't fall pregnant; the whole process was very traumatic. After this we decided to adopt. We adopted twins in 2010.

23. My greatest concern has been not being able to provide for my family. I always feel like I have to work because I don't want my illness to restrict what we should have. I think I would have had a better career had I not been co-infected. I didn't work for a long period of time and instead we fostered children because I couldn't physically go out and work. I feel a huge amount of pressure since adopting my children as I need to make sure they will be looked after if I die.

24. My haemophilia did have an impact on my life, but career wise my infection has had a larger impact as it affected the career path I had chosen for myself.

25. At present I am Chief Executive of a counselling company which offers support for people aged between 16 and 25 years. They are aware of my condition because a week before the Inquiry started a reporter contacted my work place having found me on LinkedIn. I was not happy about this but not too concerned because all of my staff are qualified Counsellors so I am hoping they are not going to be too judgmental.

26. My bowel intussusception is an assumed side effect from the HIV infection. They believe it is to do with the bacteria from HIV.

27. Other infections I have contracted have been made worse because I did not have a strong enough immune system to fight them off. In the past I have also had shingles. I was diagnosed with Alopecia when I was 18. This lasted for 7 years, until I was 25.

28. Currently, I take one tablet a day. The side effects are not as bad now but my bowel movements have never been the same. Sometimes I would feel sick in the morning and I would want to go back to bed as I felt worn out. Every time I take a pill it reminds me that I have HIV. Sometimes I feel as though life revolves around having HIV.

29. I have not been to the dentist for 5 years because I am unable to find a dentist that would treat me. I have suffered with Gingivitis which is a dental issue.

30. When travelling abroad I have to take my medication and therefore I have to have letter to say what it is for. I do not like this; I like my condition to remain confidential. In order to get visa to go to America I had to state I have HIV; it made me feel like a leper.

## **Section 6. Treatment/care/support**

31. In 2003 I had a brain hemorrhage when my wife and I were on holiday in Fuerteventura. I was left for 48 hours before I was treated because of my HIV status. After 48 hours I was air lifted to a hospital in Grand Canaria. It was very traumatic. I had a severe bleed to my brain and was suffering from a severe headache. In the helicopter I was clinging on to my Factor 8. As I was HIV positive the Doctors were refusing to give me treatment and I did not receive any for 2 days.

32. I have never been offered counseling.

33. When I was first diagnosed with HIV and I was in hospital, there would always be students peering through the windows and talking which made me feel uncomfortable.

34. To date, I still have a psychological barrier to taking Factor 8 Concentrate. There is still a part of me that believes it has something destructive inside of it.

35. It is concerning to think that if I did die people would find out about my infections. I worry about the impact it will have on my family. My mum GRO-C GRO-C always blamed herself for me being infected. She used to say "I can't believe I gave him those injections and it has given him HIV".

### **Section 7. Financial Assistance**

36. In 1990 I received a £20,000 payout due to being infected with HIV. I found out I was eligible on the radio. I had to go through solicitors who at the time were government appointed. I was made to sign a waiver in order to receive the money. I was unhappy about the waiver because it was different dependent on your circumstances. You received more money if you had kids or were married. At the time everyone felt extremely pressured to sign the waiver as we were told if one person didn't sign it then no one would receive the money.

37. In 2000 I received £20,000 in respect of the Hepatitis C. This again was dependent on your circumstances. Those who had liver cancer as a result of the Hepatitis C received £25,000. I found out this information from the Haemophilia group.

38. The two lump sum payments from the Trust were put towards the house. I also used the money I received to pay for IVF. We would have continued paying for IVF if we had had the money.

39. I currently receive £1500 a month and £300 for the children.

40. I believe there are numerous problems with the Macfarlane Trust. I do not think it is fair that those who work are penalized for doing so and those who do not receive more money from the Trust. The whole process at the



Macfarlane Trust is means tested. I believe we should all be treated the same as we are all in the same boat medically.

41. I received appliances from the Macfarlane Trust once I became a bit more militant and started speaking up for myself. The process of applying to the Trust was horrific. When I had to apply for appliances I was asked to prove my need for a washing machine. In order to get a mattress I had to get quotes and a letter from the Doctor. It felt like I was constantly begging and it was so undignified. There were a lot of things that we needed but it was such a traumatic experience to go through each time that in the end I gave up.

42. There was a time when I became very ill and could not work. I was unable to pay the mortgage and my wife had to cash in her life insurance to support us. I was on benefits for a while and it was very upsetting having to fill out the numerous forms. If my original plan of being a Mortuary Technician had happened then I would have been earning a lot more over the years. The main concern I have is what will happen to my wife and children if I drop down dead. I do not feel financially stable as if anything happened to me then my wife and kids could be out on the streets.

43. It is upsetting not being able to afford a holiday once a year. Sometimes I feel as though I just need to escape from everything.

### **Other Issues**

44. I believe that being compensated for what the NHS has done to us should have happened a long time ago. It should not have been a 30 year traumatic journey. I do not know one infected haemophiliac who has not been traumatized by this whole situation. At the time of writing this I believe an apology will not be enough. I would like a lump sum so I can pay off the mortgage.

**Anonymity, disclosure and redaction**

45. I do not wish to apply for anonymity and I understand that this statement will be published and disclosed to the Inquiry. I am happy to give oral evidence, if required.

**Statement of Truth**

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

Signed... GRO-C .....  
MICHAEL MASON

Dated...01/05/2019.....

## **MEDICAL SUMMARY**

**(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)**