

Witness Name: CAROLINE MASON

Statement No: WITN2925001

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROLINE MASON

I, Caroline Mason will say as follows:-

Section 1. Introduction

1. My name is Caroline Mason. I live at GRO-C Leicestershire, GRO-C with my husband Michael Mason (Mick) and our two daughters Natalie and Nicole. I was born on GRO-C 1967.
2. I write this statement with regards to my husband, Mick who was born on GRO-C GRO-C 1967. Mick is a severe Haemophiliac type A. He was infected with Hepatitis B Virus (HBV), Hepatitis C Virus (HCV) and Human Immune Deficiency Virus (HIV) because he was given contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my husband's full medical records.

Section 2. How Affected

4. I did not know my husband when he found out about his HIV status. I refer to the statement that he has also given to the Inquiry.

5. I met Mick in April 1989. My cousin was friends with him and he had introduced me to Mick. At that time I was not interested in a serious relationship. We used to all go out as a group of friends. My cousin had told me everything about Mick and that he was a haemophiliac and HIV positive. My cousin and I were really close at the time.
6. In June 1989 I started having feelings for Mick. My cousin had told me everything about Mick's condition as he was conscious about the impact that this might have on any future relationship. This did not affect my feelings for Mick.
7. I started seeing Mick and I told him that my cousin had told me all about him. I wanted to be completely honest with him as it did not bother me. At first he denied it and told me to leave. He got angry with me because I knew. I said that I knew it was true and eventually he said that he was infected and we stayed up all night talking about it. We talked about what it meant, the effects it would have and the consequences.
8. We got engaged in October 1989 and we were married in August 1990.
9. Mick told me about how he found out about his HIV infection. He told me that when he was 18 he received a diet sheet in the post from the Haemophilia Centre (HC) at the Queen Elizabeth Medical Centre, Birmingham. The diet sheet gave information on what diet a person with HIV should eat dependent on whether they were symptomatic or asymptomatic. He said that he had telephoned the HC to ask why he had been sent this information. They advised him that they could not discuss this over the telephone and he would need to wait for an appointment with the consultant. My husband then rang his GP who advised him that he had known for approximately 18 months about his HIV status as he had received a letter from the HC. At no point during his appointments at the HC had my husband been advised of this.

10. My husband told me that when he eventually saw the consultant (Dr Hill) he was advised that he had contracted non A non B Hepatitis (now known as HCV) and HIV and that he had approximately 12 months to live as there was no treatment or cure. He was told not to have sex, but was not given any real detail concerning the risks of secondary infection.
11. I thought the way my husband had been told such important information was extremely insensitive.
12. After I had met Mick I attended every appointment with him at the Haemophilia Unit. At no point was I offered any advice or information concerning the risk to me or how to prevent infection. We were supplied with free condoms, but we were never asked if we were using them. The only information available to me was a government leaflet from the Don't Die of Ignorance or Tombstone campaign and verbal information I received from the National AIDS Helpline. The most effective support, advice and information I received was from a local HIV charity (Birmingham Body Positive).

Section 3. Other Infections

13. In 2000 Mick was advised that he had been exposed to blood from a donor who had died of vCJD. This had a profound effect on him psychologically and as a result he began refusing all blood based treatment for his haemophilia.
14. I remember reading the letter that advised Mick he had been exposed to vCJD and just collapsing on the floor in disbelief that this could happen again. I remember clearly feeling that there really could not be anymore "infections".
15. This had a profound effect on him psychologically and as a result of this he began refusing all blood based treatment for his haemophilia. He decided to make his "treatment strike" public to raise awareness of what was happening to the haemophiliac community in the UK. He contacted national newspapers and local television outlets. Suddenly as a couple we were very exposed and it was a difficult time as we had no idea how extended friends, family and neighbours would react to the news. We had heard about people with HIV

being shunned by their local community and of those who had experienced violence and one who had had their house burnt down as a result. I felt that we had to force the NHS to provide safe care for Mick and the only way to do that was to expose our private life and risk being ostracized. I remember being really afraid about what the consequences to us could be.

Section 4. Consent

16. Mick was tested without his knowledge. His first positive HIV test was in 1983, yet he only found out in 1985. This testing was without his consent. Mick was also not given any information at all.

17. I believe that the haemophilia community affected by HIV and Hepatitis C were used as a test group to research how these infections would progress.

Section 5. Impact of the Infection

18. When I met Mick I was working as a financial advisor for JP finance which was a company specializing in corporate mortgages. I made the mistake of being honest and telling my employer and colleagues there about Mick's haemophilia and HIV status. I naïvely expected people to feel empathy for his situation. I should not have told them as after this I faced various subtle forms of discrimination.

19. It was shortly after this that Mick came into the office to celebrate our engagement and we had a tea party. As soon as Mick left all our cups were immediately removed and bleached. I noticed that I stopped being invited out with colleagues and my desk was moved to an isolated area to what seemed like a small cupboard. Jokes were being made about HIV and AIDS which seemed acceptable to the bosses and they were being directed at me.

20. I was responsible for recruiting and training staff and this role was taken away from me. I was successful within the business having started in the financial service sector at a young age. I owned a company car and I was earning well. I was accused of stealing objects and then a colleague was sacked for misconduct and my boss accused me of having an affair with him. This was all untrue; my boss had actually been to our wedding and knew I was very happily married. I felt that all this was because I had been honest and told my boss and colleagues about Mick. I eventually was pushed to the point where I rang Mick one day and asked him to come and pick me up. I left JP Finance and I didn't return.
21. I started temping for a while doing admin jobs until 8 months later I was employed by a company dealing with domestic mortgages for Bryant Homes. Having been treated so badly by my previous boss at JP Finance I told no one about Mick; not even about his haemophilia. There were a lot of articles in the papers about haemophiliacs and HIV at the time and I did not want people to put two and two together.
22. At that time Freddie Mercury died of an AIDS related illness and my manager at the time who was a big Queen fan told me that he would never listen to another Queen song again as he hated gays and they deserved to die of AIDS. I was horrified by this and I was glad that I had been cautious and not disclosed information about any of Mick's illnesses. I had to endure ongoing jokes about HIV whilst all the time keeping Mick's condition a secret.
23. I was involved in an organisation called Birmingham Body Positive attending a carers group which subsequently became a bereavement group. It was a fantastic and supportive atmosphere; I was neither judged nor stigmatized. It was refreshing to be involved in something where I could be myself. I became a part-time administrative assistant which was a substantial step back from my career in finance but I felt comfortable there; everyone was open and honest.
24. I was there until 2000 and I then did voluntary work with the Terrence Higgins Trust. They employed me from 2001 as a Court Division Worker. At the

same time I was doing a degree at Wolverhampton University in Religious Studies and Special Needs. Mick had a series of illnesses during this time suffering with shingles and an intussusceptive bowel which left him very ill. He was hospitalised and as a result I missed a whole semester to look after him. To prove extenuating circumstances to the University I had to tell them that Mick was HIV positive so they would not drop me from the course. It was hard for me to do that as I had to divulge private information to them so that I could continue to do the course. In hindsight I have also realised that I was suffering from depression at this time.

25. The Terrence Higgins Trust was initially a good employer. They understood my family life and initially gave me time off work to look after Mick. However even within that organisation there were difficulties and stigmas attached. There were divisions between the different groups of sufferers. I remember one of my colleagues saying that they were not going to get involved with the haemophiliac and HIV situation as "we know the Government will never address it because one day it will all go away" which meant to me that they're all going to die and then it will. One of the Directors said "all they want is an apology but once they get that they will sue the Government". There were huge misconceptions and the organisation changed. It was not the caring organisation it was when it started. I was made redundant in 2017.

26. Whilst I felt I was not judged working with the Terrence Higgins Trust I did find it difficult away from work. People would ask why I was working for an organisation like that. There was stigma attached. I did not tell people of our situation; I would not let people judge me. Some of our family members have been reticent to disclose Mick's status due to fear of negative reactions. I remember when I was taking part in a sponsored event to raise funds for a HIV charity; my sister, who I am very close to, refused to ask any of her friends or colleagues to sponsor me as she feared people may ask too many questions or be unwilling to support a HIV charity.

27. GRO-C

28. Whilst I was working at JP Finance Mick was quite ill. He was an extremely positive person but he came from a difficult family background; GRO-C

GRO-C When we were first married and before he started treatment we lived in constant fear that his CD4 count would drop and that he would be diagnosed with AIDS and at this time it would have meant death without a doubt. Every month he would be tested and we waited in fear for the results. Often Mick's level had dropped plunging me into a pit of fear that he would die. When I first met Mick the Consultant at the Haemophilia centre had advised me that I would be lucky if he lived for more than 2 years so we had started our married life expecting him to die and waiting for it to happen.

29. Every Birthday, Christmas and Anniversary was accompanied by internalised fear that this would be the last one we would celebrate together. However, after about 3 years of being together when it was obvious that he was not going to die anytime soon we made the conscious decision that we would not carry on this way and that we would focus on living.

30. Mick resisted treatment for his infections due to side effects but in 1990 he was asked whether he wanted to be involved in the pilot scheme for sperm washing. We agreed to this but unfortunately as a result of the treatment for his HIV his sperm quality was not good enough and we were advised that we should not try anymore for children.

31. He felt yet again he was to blame for the limitations in life which were caused by him. I had married him however thinking that we could never have children because that is what we had been told. After this we decided to live for life and be grateful for every day.

32. However, between 2004 and 2007 Mick's sperm quality recovered and we attended the Chelsea and Westminster Hospital on a private basis for

infertility treatment. This was unsuccessful. Whilst I always produced good quality embryos; he always felt that it was his fault that the IVF did not work. However, I also blamed myself. It was a particularly difficult time with a lot of pressure on both of us.

33. This had been a particularly difficult time, my body and mind were all over the place. I was having hormone injections; I would have severe mood swings and often get very angry for no reason. We were both working and both hoping the treatment would eventually work. However after spending £15,000 we ran out of money. Our relationship was strained immensely.

34. I had always been keen to adopt children but Mick wanted to avoid this. I think it was mainly because he would have to explain everything again; his haemophilia and his HIV infection. It was a devastating time for us.

35. When we were on holiday in Fuerteventura in 2003 Mick had a severe brain haemorrhage. He was treated very badly and had extreme difficulties accessing medical care due to his HIV status. We were left without care in the hospital for a considerable time and as a result of this delay I believe that Mick has been left with permanent brain damage.

36. I believe this and all the fertility treatment caused my severe reactive depression and eventually I started having counselling. The McFarlane Trust contributed £45 to each of my six sessions and I paid the balance. However, I did not actually tell the counsellor about Mick and that he had HIV. I don't know why I did not tell her but I felt that I might be stigmatised and given counselling in a different way because of it. My sessions were never going to be effective because I wasn't being open. I was determined not to take any more medication after all the tablets I had taken for the fertility treatment.

37. At the end of 2008 Mick said that he would look into adoption. This gave me a focus to be well.

38. We started the adoption process; we knew it would be difficult. It was fairly intrusive and Mick's condition was scrutinised. We had a great social worker and medical officer who took the haemophilia and HIV out of the equation;

although it was still a difficult process as we had to address all the issues once again. Even though Mick and I had been foster carers from 1994 to 2004 for teenagers everything had to be revisited.

39. When you are adopting, social groups are formed. We did not feel we could be transparent and we did not become involved. I am an open and honest person and I feel our secret raises barriers and I have difficulty forming close relationships with friends. It is extremely isolating and I tend to internalise everything.

40. In December 2010 we adopted our twin girls Natalie and Nicole; they were 22 months old when they came to us. We have been very busy since then and fortunately the girls did not have emotional issues. I am now able to recognise if my depression returns and I am able to control it.

41. We have made friends through our children with other parents. I do not tell people about Mick and his condition although if I was directly asked I would. Mick walks with a limp and if I was asked why then I would tell people. I have become very close to one of the mums from school and I now feel I am in a difficult situation and am being dishonest because I have not told her. I feel disingenuous. For the major part of my life I have created a constant invisible barrier which created to a certain extent between Mick and I but this has dissipated.

42. Mick has been on medication since the 1990's which started with combination therapy (HAART). The first combination included 26 tablets to be taken at exactly the same time each day; it also involved dietary restrictions to ensure maximum effect. He is currently taking Odefsi, one tablet a day.

43. In the mid 1990s he started interferon treatment for his Hepatitis C. Mick was able to tolerate this for 19 weeks and then had to stop the treatment due to suicidal thoughts, severe mood swings and depression. In 2017 he went on the Vosevi trial and successfully cleared HCV. The side effects of this however were horrific with headaches, nausea, fatigue, weakness, insomnia and lack of energy.

44. During the treatments for his HCV in the mid 1990s, he received interferon treatment – this was a 52 week course. Mick was only able to tolerate 19 weeks as the side effects were so severe. He had suicidal thoughts and intense depression.

Section 6. Treatment/care/support

45. In 2003, whilst in Fuerteventura Mick had a severe brain haemorrhage caused by his haemophilia, he experienced extreme difficulties in accessing medical care due to his HIV status. We were left without care in the hospital for over 12 hours, despite me repeatedly asking for someone to help him. Staff who attended him were fully gowned and treated him with contempt, fear and disrespect. Their general attitude was that he “must have taken a drug that had caused his brain haemorrhage and he therefore deserved it”. Eventually he was transferred to a major hospital on Gran Canaria that had a haemophilia unit. For 12 months after this he experienced difficulties with his sight and memory. Without a doubt the delay in effective treatment, which I believe was caused by the discrimination displayed by the medical staff in Fuerteventura, contributed to the severity of the effects of this bleed. Mick has never fully recovered from the brain damage that this caused and is still affected by; a blind spot in his vision on the left hand side of his head, difficulty articulating words at times of stress or tiredness, memory loss with regard to events, short term memory loss, inability to visualise things and a deep sense of anxiety around any type of new experience.

46. The only support I have ever been offered was a meeting with a Social Worker when Mick and I were first engaged. This meeting consisted of the social worker explaining to me how important it was that Mick made a will and

how careful we should be when being intimate. She advised me that “non-penetrative sex could be just as much fun”.

47. During Mick’s hospital stays between 1985 and 1988 Mick would be isolated in a single room. Staff would only attend on him if they were dressed in full infection control outfits.

48. Mick finds it difficult to access dental treatment as he does not want to tell new providers of his HIV status and to go through everything again. The hospital where he has his treatment for bleeds does not have a dental section.

49. I find it difficult to access support services. It would be helpful to access a carer support group but I have been unable to find one. There are only support groups for cancer patients and relatives.

Section 7. Financial Assistance

50. Mick found out about some financial assistance that was available in the early 1990s this information had come from the Birmingham Body Positive group. We received a Stage 1 payment from the Skipton fund of £20,000. We also receive regular payments from the MacFarlane Trust with subsidiary payments received for things like boiler repairs and moving house. Mick has referred to all the financial assistance we have had within his statement.

51. I have received payments from the McFarlane Trust in the sum of £45 for each of 6 counselling sessions I received for depression. However, it was difficult to access as I had to admit that I had depression and Mick had to request the funds on my behalf. It was demeaning for me to have to ask him to do it.

52. The whole financial application process to the McFarlane Trust was very involved and degrading. It felt like you were pleading with them for help. The process was complicated by having to provide a lot of evidence around

financial means, health information and we had to provide three quotes for everything. These difficulties were compounded by mounting evidence that the MacFarlane Trust staff were allowed to operate in a "gossip culture", several people with haemophilia appeared to know who had received financial assistance and for what purposes. This did not instil confidence around confidentiality or discretion.

53. The main difficulty we have experienced is that we have nearly always worked through our lifetime and have tried to contribute to society. As a result we feel penalised in that we felt we had no right to apply when we needed financial help and that as we worked we would be unsuccessful as not deemed poor enough.

54. Our perception of these organisations, in particular the MacFarlane Trust, was that they projected an ethos of judgement and inequality that made accessing financial support difficult and demeaning.

55. The amount of money given has by no means been the equivalent of a decent/average wage. It has also never been enough to secure savings which could be used to provide security for the future of our family if Mick died. I know this is a constant worry for my husband. We do not know how long Mick will live and whilst we have been able to secure very expensive life insurance this will only be paid in the event of an accident or heart attack and not if Mick dies as a result of HIV/AIDS related illnesses.

56. Over several years I have heard about the varying levels of support people were receiving. Several times during my dealings with the MacFarlane Trust (MFT) I have been shocked by the attitude of their employees:

57. During an information weekend organised by the Birchgrove Group, the then CEO of the MFT stated to me that "I will be advising my staff to scrutinize all requests for specialist mattresses (memory foam) as I have heard people telling each other to apply for them". This gave me the impression that he felt applicants would try to defraud the MFT and were not honest about their needs.

58. During the same conversation he advised me that certain registrants should not be receiving support at all as they were earning "decent salaries" which reinforced my feelings that we should not apply for anything because we both worked.

59. A Finance Officer from the MFT was asked by a person with haemophilia who she was and why she was attending a meeting, she replied "I am the person who pays your wages". I was extremely shocked by both the assumption that anything the MFT provided could be construed as a wage and her rude and arrogant attitude. Later she also advised the same person that their devotion to their dog was what she saw as "ridiculous when people substitute pets for children". I felt this displayed a clear lack of understanding around the issues concerning HIV and having children.

60. During discussions surrounding the Government lump sum issues the CEO said to me "these people would not know how to handle this amount of money" and that "they would end up in a worse situation financially". These were the people that the officials were listening to and turned to for advice around how to handle the situation.

61. The above highlights the lack of knowledge, experience and understanding of the MFT to the haemophilia community's experiences and needs. It also reinforced my perception as an organisation that could not be relied upon to be fair or treat people with equality.

Section 8. Other Issues

62. I was raised to believe that the UK had the best health care and the most honest government in the world and that as British citizens our government would never let us down. This was such a naive and mis-guided belief and has been disproved to me so many times over the last 30 years.

63. I have had countless experiences where my belief in the goodness of people, organisations, the medical profession and my government has been destroyed. I have realised that people and this country really don't care about what has happened to my husband and the haemophilia community. This is devastating to deal with and permeates everything in our life. I worked for many years for a large HIV Charity and even they did not want to support the haemophilia community, their view, "The Government knows that eventually this problem will go away" meaning that eventually my husband and all of the people with haemophilia infected with HIV will die and they won't have to worry about this anymore.

64. The medical staff that we encountered seemed intent on segregating the haemophilia community. Mick was asked not to discuss his HIV status in the clinic waiting room as this may upset other patients. The fear and shame that was already underlying our life was reinforced when we were advised not to tell anyone, even our closest family members. We were encouraged to stay quiet, stay invisible or terrible things may happen. At a time when the haemophilia community needed to come together Consultants, medical staff and the Haemophilia Society seemed determined to segregate people

65. To sum up the impact of these infections on my life since meeting and marrying Mick almost 30 years ago all I can say is it has been a series of appalling revelations about the behaviour of officials; distressing levels of fear and grief. In addition feelings of being overwhelmed when his additional infections were discovered; I had naively thought when we got married that Haemophilia and HIV were as bad as it could get.

Anonymity

66. I do not wish to apply for anonymity and I understand that this statement will be published and disclosed as part of 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**
CAROLINE MASON

Dated ...30th April 2019.....