

Witness Name: Michael Lyons

Statement No.: WITN2304001

Exhibits: WITN2304002-004

Dated: 24th June 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MICHAEL LYONS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23rd April 2020.

I, Michael Lyons, will say as follows: -

Section 1. Introduction

1. My name is Michael Lyons. My date of birth is GRO-C 1954 and my address is known to the Inquiry. I currently work for the M.O.D. in bomb disposal and have been in that role for the last thirteen years. I intend to speak about my brothers John Francis Lyons and James Lyons who both contracted HIV as a result of receiving blood products to treat their haemophilia. John was born on the GRO-C 1940 and passed away on 10th November 1986, I exhibit the death certificate under **WITN2304002**. James was born on the GRO-C 1947 and passed away on the 2nd October 1991, I exhibit the death certificate under **WITN2304003**. I will speak in particular about the nature of their illness, how the illness affected them, the treatment they received and the impact it had on their and our lives together as a family.

2. I do not wish to be anonymous for this statement.

Section 2. How Infected

3. James was the brother I first knew really. Growing up he played with me and defended me when we were outside. James was always a very nice person, he was sensitive to others. He was very well read and growing up he would help me with my reading whenever he could. He taught me to read some of the great classics in literature from a very early age. I have memories from a young age, where we were always visiting James in hospital; at times he was in hospital for nearly a year at a time. Other times I was told by my parents to be as quiet as possible, otherwise loud noises would aggravate the pain my brother was in. This was due to bleeds in his knee and elbow joints. This is where a lot of nerves come near the surface and the swelling would compress these nerves against the bone causing great pain. After the swelling died down, it would leave a residue of calcium around the joint which over time reduced movement and also, due to its roughness, would induce further bleeding. He was prescribed strong pain killers that would also have the side effect of causing disturbing hallucinations. Despite all of his health issues from his haemophilia, James studied literature and photography, and I am sure, were it not for his illness stopping him at regular intervals throughout his life, he would have done great things.
4. John was my oldest brother by fourteen years, and as he was always away working abroad during my formative years, I didn't really get to know him properly until I was around twelve years old. Before then, he would appear twice a year: once at Christmas and once during the year when he could get time off from work to visit. I was always very excited to see my big brother again. John was an outgoing person and a real role model for me growing up. Despite all of his health issues, he educated himself and became a Finance Director for some of the largest companies in the world. He had worked for large conglomerates and film production companies like MGM, all

over the world. I was very close to John, we had a really good connection with each other. Haemophilia was something that could put both my brothers out of action for quite some time, so they had to learn to keep bouncing back from these setbacks, and that was something that I greatly respected about them both.

5. As far as I am aware, my brothers were infected with HIV whilst receiving either Factor VIII or cryoprecipitate to treat their haemophilia A at the Edinburgh Royal Infirmary Haemophilia Unit. It was Dr Ludlam that was in charge of their care whilst they received treatment there. I could not say exactly when my brothers were infected but I think it would have been sometime in the 1980s. John moved to Denmark one week after the birth of his son Lars on the GRO-C 1969. He moved back to the UK in either July or August of 1984 before returning to Denmark in the spring of 1986, where he died later that year. From this timeline I can say that John was infected sometime between 1984 and 1986. Realistically they could have been infected during any one of their treatments for haemophilia. It is impossible to say which one caused their infection.
6. I cannot say for certain but as far as I am aware, my brothers were never made aware there could be a risk of infection from receiving these blood products.
7. I am not aware of the date either of my brothers were diagnosed with HIV. One thing I can say for certain is that John could have been told about his infection much earlier than he was. I can say that because there was an incident sometime before John's diagnosis, I cannot say exactly when, where James had been sitting in Dr Ludlam's office waiting for him to return from somewhere and he saw some files on Dr Ludlam's desk. James was a bit nosey so he had a look at the names on the files and saw John's file there. When he looked at the file, it stated that John was HIV positive but John had not been told that. John was absolutely livid when found out. He had recently been divorced and was having relations with other women but he also had children and an ex-partner to think about. There were so many

people in his life put at risk by not telling him that information. I cannot remember how Dr Ludlam responded to John after he had found that out but the information was there and John wasn't told.

Section 3. Other Infections

8. I am not sure whether my brothers ever contracted any other infection other than HIV.

Section 4. Consent

9. I am sure that my brothers were tested without their knowledge or consent. The incident where James found John's file containing a note that he was HIV positive shows that at the very least, John was tested for HIV without his knowledge or consent.
10. I could not say for sure whether my brothers were ever treated or tested without being given full or adequate information.
11. My brothers were tested for research purposes. I remember them mentioning that to me at one stage many years ago. I cannot remember the specifics of why they were being tested for research, it could have been related to the haemophilia, but I know that they were tested for research at some point at the Edinburgh Royal Infirmary under the care of Dr Ludlam.

Section 5. Impact

12. I think the mental effect on my brothers being infected with HIV was devastating. At the time they were diagnosed, HIV was something that was only associated with people who were homosexual, there wasn't another category of people in the public eye who had been infected from blood products. To be associated with that was another layer of stigma for them on top of the having the disease. I think that both my brothers liked a drink, but after their diagnosis that took on another perspective. I remember the last

holiday I went on with my brother John, we were down in Cornwall together. One day he was sitting across from me in the pub and he asked if I would like to have sip of his pint. I said okay and took a drink of it but I knew what he was trying to ask me. Did I fear being near him, or something along those lines, I knew it must have been something that weighed on him during that time. That stigma was something that weighed on both of them.

13. The physical effects of the infection were something that developed over time, there wasn't a lot that was noticeable at first. Obviously there would have been a lot happening internally for them as the infection developed, but that wasn't something I saw at first. I remember once when John came to visit me in Norway, and he said that the doctor had told him that he would be dead in seven months. The decline in their health was so rapid. For those seven months for John for example, he didn't seem to be doing that badly but the infection was chipping away at him. For James, when he found out he was going to die from the infection, I went to visit him and he looked like a skeleton. When James did die, I remember seeing him and not even really being able to recognise him, the infection had changed him so much, he'd lost so much weight.
14. Due to the infection, James developed a lot of skin blotches. His skin looked very aged. I could not say exactly when he developed these blotches but I remember him coming to my wife's funeral in 1991 and when I saw him, I noticed these blotches, he just did not look well.
15. John developed liver problems during the course of his infection. He was never diagnosed with hepatitis C but just before he died he was admitted to Copenhagen Municipal Hospital due to issues with his liver. He was due to have a biopsy to assess the damage to his liver but he entered a liver coma during that stay in hospital and died a few days later. I cannot say for certain whether these liver issues were related to the infected blood products he had received but I think it is likely that it was. James did not develop any further medical conditions or complications as far as I am aware.

16. As the illness went on for my brothers, they both did what they could to keep going physically but I think it was the mental side of things that affected them most over the course of the illness. Through everything that was going on they had to deal with the idea that they were being treated like pariahs because of their infection most of the time.
17. As far as I am aware my brothers were never treated for their HIV infection. I think James began some kind of treatment before he died but I cannot remember exactly what that was. There were not a lot of treatment options available at that time, a HIV diagnosis was essentially a death sentence in those days.
18. The HIV infection would undoubtedly have had an effect on my brothers' treatment for other issues. As soon as they went in for any kind of treatment and mentioned their HIV that would completely change how they were dealt with, there would be so much more caution and apprehension from the medical staff involved.
19. The infection was devastating for my brothers' private lives too, especially for John because he had a family. There was a time when John was a bit unsure of how to interact with his children for a while. He wasn't sure if he should even be too near them in case he infected them. I know that would have been quite a blow for John to miss out on those interactions with his kids, or at least to miss the certainty of knowing he could interact with his kids. For James, he lived alone during his infection, so I know that the mental aspect of having to deal with all of that alone must have been very hard for him.
20. I could not really say what effect the infection would have had on my brothers' social lives.
21. I was stunned when I heard about my brothers' infections. That was made worse by the fact that there was nothing I could do to help them. I couldn't feel anything but helpless in a situation like that. We were living our own lives when my brothers were diagnosed, so I couldn't even help them get to

the hospital or anything like that. It was all just beyond my control. I felt like there was a clock ticking the whole time and all I could think about was how long they had left to live. When my brothers died I was just left in shock. I had been going to visit both my brothers in the hospital in their last few months, but I still couldn't process it when they died. I felt numb after they had gone.

22. One thing I found strange was that neither of my brothers' death certificates mention their infections. I believe John's does not reference a cause of death as it is a Danish document and I don't think that information is normally included. James' however was issued in the UK and does not list his infection under cause of death even though he died at the Milestone AIDS hospice in Edinburgh. I was a bit perplexed when I first saw that but I didn't read too much into it. I had assumed it was something to do with protecting the dignity of the family but I was not sure.
23. I think when my brothers were dealing with the infection, the stigma associated with HIV was a huge issue in society. There were people who thought that you could catch it just from rubbing up against people. I know that would have been a terrible time for them both because they were made to feel so different to everyone else by their infection.
24. The infection also affected other members of our family as well. I know it was very hard on my sister and my mum in particular, I know it worried them both a great deal.
25. I would not be able to say for certain what effect the infection had on my brothers' professional lives.
26. I would imagine the infection had a significant financial effect on my brothers. Just from the fact they would have to change their whole approach to their professional lives. It would change the kind of work you were able to do or even the kind of jobs you would have been able to apply for. I can't say what the effect would have been but the infection affected every part of their lives.

Section 6. Treatment, Care and Support

27. My brothers did not face any difficulties in accessing treatment, care and support as far as I am aware.
28. I do not believe that counselling or psychological support was ever offered to my brothers as far as I can remember. I think that is something that would have helped them. I know my brothers would have felt quite jaded by the medical profession because of their infection. I can't say exactly how helpful that kind of thing would have been, but any help is better than no help at all.

Section 7. Financial Assistance

29. James received £30,000 from the Macfarlane Trust but did not have any time to enjoy that money before he died due to his ill-health..
30. The Macfarlane Trust made two payments on 29th January 1992 to Johns' children and our mother. I exhibit the letter confirming these payments under **WITN2304004**. There was a payment of £2,000 to our mother and a payment of £19,500 to each of his children Lars, Siné and Jannie. I could not speak to what the application process was like for this fund. John did not mention any trouble in applying to the fund as far as I can remember but he was in a coma for around six weeks before he died so I could not say for sure.
31. As I understood it, with the Macfarlane Trust, the amount that they were to receive was to be final. That was all they were going to receive and they were not able to apply for anymore. I found that a bit strange, it was if they were saying if you don't take this or sign this then you will get nothing. I didn't think that was the right tone to take with people affected by this.
32. I have not received anything myself because of what happened to my brothers.

Section 8. Other Issues

33. I would like to point out the lack of consequences for the people who were responsible for what happened. No one has been brought to heel about this. As far as I can tell, everything seems to have been swept under the carpet right from the very beginning. From the meetings about the Inquiry I have been to, I was also shocked to hear about how so many people are dealing with having their records destroyed or go missing. If it had just been one or two records going missing you could understand that they may have just been misplaced, but to have this happening on such a large scale is unacceptable.

Statement of Truth

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

Signed GRO-C _____

Dated Jun 26, 2020