



Witness Name: John McDougall

Statement No.: WITN002850

Exhibits:

Dated: 17th January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOHN MCDUGALL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, John McDougall, will say as follows: -

Section 1. Introduction

1. My name is John McDougall, my date of birth is 1949. My address is known to the Inquiry. I am officially retired but I'm a director and chair of the number of different companies in non-executive roles. My ex-wife Kate McDougall and I were married in 1971 and divorced in May 2018. I intend to speak about my late son, Euan John William McDougall. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

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Section 2. How Affected

2. I am giving this statement in relation to my late son Euan John William McDougall. He suffered from severe haemophilia A and was born on GRO-C 1977.
3. We knew the risk of Euan's treatment as my wife Kate's, brother Terry was infected with HIV due to factor VIII treatment.
4. At the time of Euan's birth, factor VIII was a relatively new treatment. The first two years he only received this in result of a bleed and we had to take him to Yorkhill for that was where he would be given factor VIII. This continued for two years before they introduced prophylactic treatment. Parents were trained to treat on a preventative basis to avoid bleeds. This was twice a week and by injections and these were effective for around 72 hours at a time. My wife Kate gave Euan these injections after having tested on oranges because they get the same level of resistance as skin does. Home treatment would have started in around 1980 or 1981. Euan would have been about three years of age when the treatment started at home.
5. In terms of factor VIII, we always compared it to Kate's brother Terry who really thought the factor VIII was a godsend. Before that he was given cryoprecipitate, that was more difficult to do and therefore this was much more convenient. Due to this being twice per week on a prophylactic basis, if there were any risk being affected, the level of exposure was greater.
6. At the beginning, we were told to keep records by the haematology Department of the date, time and batch number of treatments. The format of this was prescribed by the doctors. They updated this twice a week. I do not currently have this to hand but I will look for this.

7. I do not believe it would just have been us keeping a record. From all that data and among those who had contracted HIV, it would be easy to work out what batch and who was infected. The records also indicated when heat treated batches commenced, in January 1985, among other matters.
8. Euan was diagnosed with HIV in 1985 in around March. Kate's brother Terry McStay was 18 months younger than her. He was the first haemophiliac in Scotland to die of HIV. He died in November of 1984. 18 months before his death, Terry went to live in Newcastle to be treated by a Dr Jones who was recognised as the leading HIV expert in the UK. He would be around 32 or 33 years of age when he went to see Dr Jones. He was getting the best treatment he could. Terry's HIV accelerated into AIDS fairly early on in 1984. It had developed into AIDS by May of 1984. This is when Terry was in Newcastle. Terry was sending messages and phoning and said that American factor VIII was the cause and told us to avoid it. We had been using American treatment with Euan as that was what was available at Yorkhill Hospital.
9. During 1984 on any occasion we could, we would avoid American products. We had asked for non-American when we were getting Euan's treatment but there were a number of occasions when only the American factor VIII was available. We had the choice of either letting the bleeding continue or treating with factor VIII where we knew there was some sort of risk. This was never communicated to us by the hospital but this was purely through Terry. I do believe that Yorkhill hospital used US factor VIII longer than others did. Other hospitals had stopped using American factor VIII by 1984 and even people we knew and staff knew to avoid US products when they could. Yorkhill were still procuring it when others had already stopped. There was pressure to heat treat as that was known to reduce risk but there was a refusal by them of doing that. They said that heat-treating could

reduce the effectiveness and I believe there were cost implications behind this too.

10. Factor VIII was typically kept cold. Terry died on November 3rd 1984. There were headlines at the time that said killer blood. They played it out in the press like a gay plague. There was a hoard of photographers outside Kate's mother's door. In the article they mentioned he was a haemophiliac, gave his name and inclined it towards him being gay and it was generally just sensationalism.
11. Most people had never heard about haemophilia so it was easier to try and imply that people were gay. There were lots of publications publicising it. Four weeks after Terry's death, they started heat treating factor VIII treatment. This is either the most remarkable coincidence or they were reacting to Terry's death.
12. Euan's first heat-treated factor VIII was in January 1985. This was within two months of Terry dying. It was in April 1985 that Euan was diagnosed as HIV positive. He was diagnosed as having HIV at eight years old.
13. We dealt with a Dr Anna Pettigrew. She was the regular clinic doctor at Yorkhill. Kate had gone in to take Euan to find out as it was a regular blood testing and that is when we were told that he had HIV. Kate came out of that meeting into the car where my father was and she never told him and never told anyone. Following his diagnosis, tests were done every six months or so, which felt relatively infrequent.
14. I believe that Kate was told that time that they wanted to have a longer time to talk about it. Within a few days, we had another meeting both with Kate and me and they told us that he was HIV positive. They told us that he would have up to 5 years for the disease to activate and said that that he would die within two years. At that

stage, we knew what the outcome would be and it turned out that was quite accurate. If you read about it at the time, all articles suggested that five-year incubation period. Euan was tested every six months or so to see if the virus had activated so Euan tested during 1985, 86, 87, 88 and 89.

15. In that first year we did a lot of things as a family such as me playing football with him and going on holidays. Twice a year we would go to Yorkhill for a while and they would say that it was not activated. This normalised for us over time.
16. On a Saturday morning in September of 1989, we got a phone call from Yorkhill that said they would like to see us very quickly. I remember driving to Erskine and we knew the reason why there was only one possible reason there could be that they wanted to see us at Yorkhill. We went the same day and they told us that the HIV virus had activated and they were going to put him onto a drug called AZT. This was seven tablets day. This turned out to be a high dosage. There were no treatments between 1985 and September 1989 when he was diagnosed. It had lain dormant until then.
17. Euan went onto AZT from then on and was still fine for a year, then it got to August or September of 1990. It was then you could see. I remember I went to football with him and within two minutes, he was sitting on the terrace, he said he was too tired after one minute of standing. He looked the same but he was very different in terms of his health. Another time we went with one of his friends to Dumbarton Rock and went up half a dozen of the steps Euan had to sit because he was so tired.
18. Euan started to lose weight by the time it got to the middle of 1991. If you saw school photos of years before he was the tallest or second tallest in the class, within the year he became the smallest and thinnest. By summer of 1991, the physical change was very drastic.

We went on holiday 1991 to Majorca. We'd still be able to get him there on holiday. We went to Tenerife in Christmas of that year but we travelled back within 40 hours because Euan became very ill. We spent the whole time we were there trying to get back as we were not able to get insurance that would allow us to get Euan back.

19. Euan spent Christmas in Yorkhill in 1991. It was more of the same with his symptoms. He was staggering on at school until about April or May of 1992. He had about 50% attendance. He was a bright boy and generally got top marks but then he just wasn't able to physically go to school.
20. By 1993, he wasn't going to school and became shier and less confident. We have home videos and in them you can see how ill and withdrawn he got over time, especially in contrast to his classmates.
21. At the beginning of 1993, Euan had difficulty with his eyesight in his left eye. He was then put on an intravenous drip for three hours every day. This made him sick every day. We had to time it for every evening, just so it that he could then go to bed and he hated it. This seemed to arrest the decline in his eyesight for a time. Following this, they changed his treatment to only weekdays and within a month he lost sight in his left eye in April 1993. Four months later his right eye went too and he became blind by approximately October 1993. Euan passed away on 12th January 1994.
22. During 1992, treatment was transferred to Ruchill hospital. Most things we had from them on were there. We dealt with Ruchill from the HIV and AIDS point of view and Yorkhill from the haemophilia point of view. Yorkhill people became a close social group for us. There were other AIDS sufferers at Ruchill and some of them were adults. Both rooms at either side of Euan's were prisoners when he was there. I recall that there were prison officers outside and it was a

very different atmosphere there. Euan did not like it. Even if you went into the sitting-room there were people smoking and Euan hated that.

23. There was a haemophilia parents group at Yorkhill and my wife was secretary of that. You got to know people well and then the ones that moved onto Ruchill we continued to know. The parents group met at the Lorne Hotel in Glasgow and we would discuss things like the dangers of American blood and how to press for heat treatment of Factor VIII.
24. The information we were given by Anna Pettigrew in May of 1985 was accurate given that Euan did live about the same amount of time, if maybe not a bit more than what she suggested.
25. I recall in 1982 I was working in Holland and I was flying from Glasgow to Amsterdam. I recall reading a newspaper and there was an article about HTL3 which was HIV under an earlier name. The word haemophilia was there and it jumped out. It seemed to mention that the risk was more because of blood products. They said it was so concentrated and they mentioned the five-year period as well. They said it could wipe out all haemophiliacs and I remember freezing while I was reading this article.
26. I do believe we should have been told the risk of HIV being contracted earlier. The parents group were talking about it in 1984, prior to Euan's diagnosis. I believe that Kate's brother, Terry's death saved dozens of others because it expedited the introduction of heat treatment of Factor VIII. I bet that no one treated following the heat treatment was contracted hepatitis C or HIV.
27. I recall there was a Dr Willoughby in the haematology Department at Yorkhill and he left for to Australia. He was in charge of the Haematology Department. The parents group would often discuss the discord in the haemophilia unit. Nurses made passing comments.

Some was perhaps sensationalist nonsense but sometimes you would hear a mix of stories. I believe that there was an unhappiness with the staff and they were working to rule at the time. This meant that they were not doing anything beyond their contractually allocated tasks.

28. If you needed something and went out of hours, the staff wouldn't do it. Senior doctors had to do it themselves. This lasted a few days or so when this happened. It's all very odd in a professional environment. I recall that it came to peak one weekend and on a Monday Dr Willoughby handed in his notice. I believe he went to Australia for higher paid job. He knew why they continued to use American blood; he's the only person who could have. I do not know if Dr Willoughby is still alive but I do know he did give a written statement to the Penrose Inquiry. As head of Haematology at Yorkhill, Dr Willoughby would be responsible for the policy to source American blood.
29. Another bit of hearsay from the parents group was that the factor VIII production centre in Edinburgh was for Scotland and Northern Ireland. I believe this was called Helen's Glen. Apparently they were making blood products from Scottish blood donations and then exporting it in exchange for American blood, which was cheaper. Scottish blood and Northern Irish blood had a higher value than the US blood, so they could sell a litre of Scottish blood and make more money. They were importing and exporting blood as far as I understand. They would use the profit to buy more blood. There was talk of the person who suggested that idea had won a holiday in the Caribbean but this could just have been hearsay from the parents group.
30. One of my main complaints is why they didn't heat-treat the product. I don't understand why it took Kate's brother, Terry's death for them to make changes. I do wonder if anyone has been infected since 1985, if they only received the Factor VIII product from then. They said that heat treatment was too expensive and would reduce effectiveness of

Factor VIII. However, that treatment was introduced weeks after Terry died.

31. The AZT that Euan was on turned out to be an overdose. I believe at the time it was hard to tell what was too much or was too little.
32. In terms of cross infection, this was all over the papers. There was a sister in Ruchill who explained about cross infection. They said things like don't share toothbrushes. We were worried about more practical things. We were worried about the social aspect of things. Euan was 8 at the time and was at school surrounded by other children. We wondered if we should tell school. We did tell his teacher and they said this was not a problem.
33. We did not speak about it with anyone and we didn't even talk to Euan about it. There was such a stigma at the time, we were worried that he would be ostracised. If he was older we'd be more concerned about sexual relations but with Euan it was more we were worried about his social contacts at the time.

Section 3. Other Infections

34. Euan was infected with HIV and did not have any other infections, other than possibly encephalitis.

Section 4. Consent

35. Euan had not been tested at the point when Terry died in November 1984. I can remember people at Terry's funeral saying we must be worried that year and we were. We did not know at that time. I remember saying that we hoped he wasn't going to be infected. I do not believe any testing was done without consent. Euan may have been tested before but we do not know. I think when they're dealing with a young child they wouldn't want parents to worry. Euan's blood

was tested in terms of his haemophilia all the time and you get used to those sorts of routines.

Section 5. Impact

36. The only treatment that Euan had in relation to his HIV was the drug AZT. He had no difficulties in accessing this treatment. He would be on half a dozen different drugs every day. He was skin and bone but he was on a lot of medications and supplements. The worst thing he had was a drip that he had for his eyes that was to try and prevent him going blind. This was three hours a day for two years.
37. From around 1985, until his HIV became active, Euan was the same confident, outgoing, sociable boy he had always been. Euan would do things like abseiling. I recall that at one point a group of haemophiliac children all went on the activity holiday. Euan was HIV positive at the time. I think all the children who went on this trip were HIV positive.
38. When Euan's condition started physically affecting him, he did become withdrawn. I can remember him saying that he was the smallest in his class. He couldn't play football as he wanted to. We have home videos of him with his friends and you can see the difference between him and his friends who are healthy.
39. In terms of any dental treatment, Euan's teeth were perfect. I remember them putting some sort of coating on his teeth to make sure that he didn't lose any. Any dental treatment Euan had would have been at Yorkhill. We do generally have happy memories of Yorkhill but the issue is policies persisting with American supplies and lack of heat treatment of Factor VIII and how it was run in terms of the blood.

40. We dealt a lot with Dr Brenda Gibson and Euan was dealt with at the same time as the leukaemia patients as she dealt with them too. Once Dr Willoughby left Yorkhill, at the clinics we would see Dr Anna Pettigrew and increasingly Dr Gibson. We saw more of Dr Gibson in around 1989 or 1990 and when Euan was on AZT. The AZT was Dr Gibson's decision and I believe that she wrote a paper on the use of AZT on children and for HIV. I believe the paper was to justify why they had the level of dosage they did. This dosage was too high.
41. In terms of the impact on our family, one clear impact is that my wife and I are now divorced. The situation we were in put strain and tension on our relationship. It gets to the point when you are not the number one for each other. I remember my wife saying that she wished it was me or herself that died rather than Euan. Euan was our top priority, and ourselves and each other were below that. This did put pressure on our relationship.
42. In the 1995, I developed a tumour on my pituitary gland. It may be unrelated but the doctors did say that a driver for this is stress. The tumour was benign. This was undiagnosed for nine years and they were able to tell this by the size of the tumour. The tumour has had major impact on my health and life.
43. In terms of our social life, we still saw our friends but we always had an eye on Euan. I remember one example when we went to the Peat Inn with friends and Euan was 11 or 12. We felt he was like an adult when he was with us in that sort of situation. We were going away for a treat and we did decide to take him, we could have sent him to his grandparents at that point. I remember he stayed in the room and we kept running back and forward, constantly going back and forward checking on him. We were always watching and checking on him, I think Euan found this quite frustrating.

44. Once Euan died, I remember finding it strange going to the urinal alone in the toilets. Euan would pee quite a lot because of his condition and treatments and any time he peed I would, sort of, go with him so it was strange not to have some standing there next to me when I was at the urinal. I got so used to always having him on my side there, it was strange without him.
45. Euan's death has had an impact beyond his passing. People treat you differently, particularly if they have children. People that have children that didn't end up in Euan's situation have children who have left school and go onto education and to graduate then onto jobs. You see people have those sorts of events in their lives and we know the contrast with our situation and I think people feel that it can be hurtful for us to hear about their children going on living their lives when Euan was not able to.
46. In terms of the stigma, I'd say one of the most amazing things is that really from 1985 until Euan's death, we did not really discuss his condition with him, we did not have that conversation but it didn't seem strange at the time. We didn't discuss it with anyone and we wanted to make sure that nothing about it got out. I remember at one point, Euan was in the Western infirmary because he had a sore lip. The doctor was treating this and then mentioned that Euan was HIV positive. The doctor started talking to Euan about it and I remember shoulder charging the doctor out of the room to stop him talking about it. This was a purely gut and natural reaction to protect Euan from it.
47. I found that work was a good outlet during this time it was an escape from what was going on. I used to travel a lot for work and I would often find myself phoning to check on Euan. I'd want to know if he was having a good or bad day quickly, before getting the full story. I worked with Honeywell prior to retiring and I don't believe it did affect my career progression because I did become a vice president. Work

really was an escape for me. I do not believe that Euan's condition had any real impact on my work or otherwise financially. I used work as a distraction. However, my wife gave up her work for eight years or so and this had major financial implications.

48. Once Euan's HIV turned in to AIDS in 1991, he would have moments where he would go paralysed for several hours. It was very scary the first time, it was just his eyes that could move. He got to know that there would be signs of this coming on. Euan could feel his lips tingling and that would be a sign that he was about to have paralysis. I do not know if this is maybe related to encephalitis. We never really knew when it would happen other than the signs. This certainly put worry in our minds and we were worried about Euan being out by himself or with his friends and then having this. I recall once, after three hours I would make jokes with Euan about him getting a move on and coming back to normal. This happened over a couple of years, maybe six or seven times. When it first happened, we did think that perhaps he would be paralysed for life but this was not the case. Each time, the total paralysis would last around three hours.

Section 6. Treatment/Care/Support

49. I do not recall any counselling or support being offered. I do not think we would have taken it. We felt like counsellors to Euan anyway.

Section 7. Financial Assistance

50. I remember we got, I believe, what was called an interim payment of £20,000 in 1993 and that was in full and final settlement of something. I cannot remember where it came from. Euan said he wanted a caravan so we went down to Blochairn to get one but the time we got there he decided he wanted a boat. We did end up buying a boat called Butterfly 23. The following day we put the boat out on Loch Lomond. The last time we went out was Euan's birthday on 28th June

1993. It then sat for a year before we sold it. All the birthday decorations were still out on the boat when we went to clear it out in spring 1994.

51. In terms financial assistance, my wife, Kate generally took care of things like the Skipton fund. I recall that 3 or 4 years ago we received a payment of £30,000. I do not know if there was any difficulties in applying for this money because we were separated then. I do not believe we have had anything from any other funds. We did not receive anything from the new fund and we do not know anything about it.
52. We are not involved in any haemophilia support groups but we are still friends with other families who had sons who were infected.
53. In terms of the adequacy of the funds, I would say that it was adequate for us but we were both working at the time. However, my wife was a teacher and gave up work for eight years to look after Euan. For us, the funds were sort of negligible but we were in a very fortunate position, but I know there are others who may not have been able to work and whose entire life has been affected in other ways. If you compare £15,000 against the hassle others have faced and that can be quite difficult.

Section 8. Other Issues

54. I did not have any involvement with the Penrose Inquiry. My wife Kate dealt with that. I felt that the views of people who were infected or affected were not really taken into account as much and there was more focus on what senior doctors were saying. There was no mention about the treating and no explanation why Yorkhill had decided to have a different policy to other hospitals.

Statement of Truth

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

Signed _____

GRO-C

Dated

24 February 2019