

Witness Name: Christina Leitch

Statement No: 1

Inquiry Reference No: PI203MF

THE PENROSE INQUIRY

Witness Statement of Christina Leitch

I, Christina Leitch, say as follows:-

1. I am [REDACTED] years of age having been born on [REDACTED]. I am now retired. I have been employed as a qualified social worker since 1978 in an adult hospital; however, at the end of October 1984 I began work in the Sick Children's Hospital, Glasgow (Yorkhill). At this time I was a Senior Social worker my role being Manager/Practitioner. This meant as well as being a manager I would also deal with some cases.

2. In my first few days at Yorkhill my manager informed me that the consultant haematologist/oncologist who was Dr Hann, had asked if a social worker could be linked to the haemophilia department. I was delighted to assume this responsibility. I had a meeting with Dr Hann and agreed that I would link into the haemophilia unit.

3. I attended the haemophilia clinics and the haemophilia nurse would introduce me to boys and their parents so it was not just when there was a problem I met with families. I can't be specific about the proportion of my time which was allocated to the haemophilia unit but I did attend weekly clinics and made visits to schools with the specialist nurse. If a child came to hospital for treatment, I would be advised by nursing staff and where possible would see the parent and child at that time. Also if a child was admitted with a bleed I would spend time with the child on the ward. Where appropriate, I made home visits especially where there were specific problems.

4. I think my first awareness of HIV was relatively soon after I arrived at Yorkhill hospital. I recall that one boy had been admitted to Yorkhill hospital with I think appendicitis. An item appeared on the television news saying that a ten year old boy with haemophilia had been admitted to Yorkhill hospital with HIV. The boy concerned knew it would be him as he was the only one in hospital at the time with haemophilia. I remember speaking to the haemophilia sister Chris Murphy about it at this time. In fact it was the haemophilia sister who told me about it. I met with the mother (for the first time) to offer some support. I don't know if I had knowledge about HIV in haemophilia patients before this news item. I remember that after I learned about it and the implications for children and families that I thought it was no wonder Dr Hann wanted a SW service for the patient group. I must acknowledge however that Dr Hann had directed me to the SW Special Interest Group and it was evident that he had experience of and valued the SW input. It was also the case that the hospital could not retain its status as a Haemophilia Centre unless the multi-disciplinary team included a social worker.

5. Dr Hann, Dr Anna Pettigrew, the haemophilia sister Chris Murphy and I met occasionally but Dr Pettigrew and Sr Murphy and met quite regularly. I was never present when any child or their parents were informed that the child had HIV. I have no idea how this was done. I think it was Chris Murphy the haemophilia sister who informed me which children were HIV positive. It was mainly Chris Murphy and Dr Anna Pettigrew who shared information with me. We kept one another up to date about the families we worked with, it was a team approach. It was never a situation of anyone saying to me, "We have just told a family their child has HIV".

6. I would make contact with families and work closely with them if there were difficulties and they wanted support/assistance. Some families tended to be distant. As I got to know the families who were affected by HIV, and could see the impact this was having on their lives. I decided to start up a Parent's Group after consulting with the parents as to whether they would want it and felt it could be of benefit. I think the Parent's Group was started in

late 1987. The group met on a Friday evening over the period of months, it was certainly less than a year. Up until this point parents may well have met one another in clinics but they were each dealing with their particular anxieties separately. They did not know who else was in the same situation. The group created an environment in which they could meet and discuss common issues openly for the first time. The Parent's Group proposal was not well received by my health colleagues. It seemed to heighten fears regarding litigation. Concern was expressed when I made it clear that the content of meetings would be confidential and therefore not shared with my health colleagues. Some parents were, at that time distancing themselves from hospital staff both medical and nursing and this was a concern both for my colleagues and for me. Parents were experiencing a range of emotions in particular they were feeling very angry with the health service and health staff felt that they were on the receiving end of that anger. I believed that offering parents the opportunity to meet as a group would be of benefit to them. There was a difference between my role and that of my colleagues and my relationships with parents were not affected by the anger, etc related to HIV because I did not work for the health service. I understood however that it was difficult for the medical and nursing staff to deal with and although there was initially, a tension in our working relationships when the parent group began, this was overcome.

7. There were all sorts of feelings arising from a child being infected with HIV. I met many parents from other parts of the country and some mothers felt guilt that their son had inherited haemophilia from them. Those mothers also had to deal with knowing they may have given their child the treatment that infected them with HIV. At times the parents I worked with in Yorkhill felt intensely angry. Some referred particularly to Dr Willoughby and viewed the fact that he went to Australia at the time this news was breaking, was linked. They felt he had abandoned them.

8. In respect of the Parent's Group, the confidentiality issue was dealt with by my meeting everyone individually and explaining that walking in the room would be a sharing of information. That everyone had to commit to total

confidentiality and that my assessment was that no one in the group was, in my opinion, likely to do other than have complete respect for that. The meeting place was a social work venue away from the hospital and only my manager and I knew the purpose of the group.

9. The isolation and stigma related to HIV had left people feeling powerless. The group lessened that and empowered parents to some degree. After the group stopped meeting, a natural ending, parents were able to remain in contact to support one another. It had also allowed me to form a more effective professional relationship with them independent of my role as part of the ward team. There was I believe, a high level of trust. When the group ended I continued to meet parents on an individual basis, normally at home and in some instances, late evening to allow for privacy in the family home.

10. At the time of the Parent's Group the Haemophilia Society were campaigning for compensation. Parents who felt they wanted to support the campaign and write to the elected representatives were frustrated by the need to maintain secrecy as to identity. I enabled them to do that by advising the parents if they wanted to write a letter to their MP they could give me sealed envelopes which I would put it in a second envelope with a cover letter to confirm their letter as being genuine and inviting recipients to reply in similar manner.

11. I was a founding member of the Macfarlane Trust which was set up in 1988 and began making payments in 1989. The Haemophilia Society appointed some trustees however my appointment was a government appointment.

12. I recall once, although I cannot recall what year this was, I went to visit a boy who had haemophilia and HIV while he was in hospital. The boy had been put in isolation. I was informed by haemophilia sister Chris Murphy and Dr Anna Pettigrew that the hospital had brought in this procedure and we had to go in to see him "gowned up". They explained that they had been told that

we had to do this as it was hospital policy. I responded that as I was not employed by the hospital I would not consider myself bound by that but went on to express my concern as to the message we would be giving to young people and their parents. Such measures were totally different from the guidance we gave to schools and families. We told other people that these measures were unnecessary. This was not the approach we promoted. I said I would refuse to wear a gown etc but recognised that I was in a different position from Chris Murphy and Dr Anna Pettigrew who were health employees. They then both replied that we would all go the ward together at that point, and be prepared to stand our ground. they were doing the same. We did go in and see the boy, without gowns, etc,. I recall being in his room when lunch arrived. I think Sr Murphy was present too. A nurse came in with the boy's meal on a paper plate. It was placed on top of a crockery plate from which it was slipped over to him. The nurse was wearing gloves, gown etc. The boy laughed when he looked at the mince and beans wobbling on a plate, and said, "This is what it's been like, can you imagine eating this off a paper plate". His parents felt awful and saw their son as being hideously stigmatised. He is one of the boys who later died. He was a fine young man. I feel very emotional thinking about it.

13. On an ongoing basis Sister Murphy and I often did joint home visits but we each visited families at home on an individual basis.

14. I do recall presenting a paper to a national conference set up by the Haemophilia Society. The conference was held at the College of Physicians and Surgeons in Glasgow. I got the parent's permission before doing this because the content of the paper related to their experiences and their children's lives. The parent's were happy for me to do but agreed after discussion as to the purpose and value of the paper. One parent said they felt some people were making a career out of working with HIV and publishing papers.

15. I cannot say when I actually became aware of Non A Non B Hepatitis. However, it was at a lunch time seminar and I recall Dr Hann was there. The

discussions were of the implications of Non A Non B coming from infected blood products. There were also discussions of heat treating Factor VIII. As I recall it, it was being said that this was a significant problem but with heat treating and screening there was no need for concern. One Consultant who was present from another hospital, who seemed to me to have specialist knowledge was giving presentation although Dr Hann facilitated the seminar. Dr Hann at one point asked his colleague, "If by some genetic mutation you found that one of your family had haemophilia would you be happy giving them Factor VIII treatment?" The reply was no.

16. I recall doing a home visit with Dr Pettigrew to one boy who had not been infected with HIV but who had hepatitis. Sr Murphy had commented to me that she was surprised that this boy did not have HIV given his age and treatment history. Dr Pettigrew discussed with the mother the measures she should take to protect the family with regard to towel usage and crockery. I don't recall this being the time the family was told but rather that this was a follow up visit. On reflection, my feeling about the meeting is that the mother already knew her son was infected and this was a reinforcing visit rather than advising him that he was infected. What I remember clearly about the visit was that the mother responded very indignantly when Dr Pettigrew advised her to ensure no one else in the family used the same towel as the boy. She made it very clear that no one in her house ever used the same towel as any other member of the family and that towels were used once only. I don't remember her reacting strongly to anything else being said. If this was when the mother was given the news for the first time, then I can only say that I do not remember it. I cannot remember any other joint visit with Dr Pettigrew.

17. Obviously discussions with parents also centred around the future for the boys. Will they go on to develop full blown AIDS? At first 10% was being quoted as the number who would go on to develop full blown AIDS. Then the percentages began to rise until it got to 75%. One mother said to me, "They are all going to die, aren't they?"

18. The arrival of Hepatitis C brought the same fears and anxiety as had HIV. There was just this feeling of it couldn't get any worse. Parents and adults I met at that time spoke about how Factor VIII had transformed lives and given such hopes but had turned out to be something that was taking and destroying lives.

19. By the time I left Yorkhill hospital at the end of March 1992 all of the boys I was working with had been transferred to the adult hospital. By that time I had allocated another Social Worker to the Haemophilia Unit to work with families of younger children so that I could focus my attention on this particular group.

20. In my view children with bleeding disorders were not regarded in the same way as the oncology patients on the ward. Some nursing staff treated the two patient groups very differently. I recall Sister Murphy and I discussing this on one occasion but also discussing it with my social work colleague who spent a very large proportion of her time on that ward working with families of children with cancers. My social work colleague expressed her concern to me that children with bleeding disorders were treated like "second class citizens" when they were in-patients. That applied to all haemophilia patients and not just the ones who had contracted HIV. It seemed to be that because they were not ill but perhaps admitted with e.g. a knee bleed that they were viewed with less sympathy. They were children who would not be lying in bed sick but who could be lively at times.

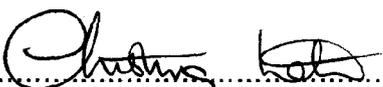
21. The first child to die in Yorkhill that I am aware of, who was infected with HIV, was a baby who had been adopted from an orphanage in another country. The child's health status had not previously been known by the parents. The child did not have haemophilia. The levels of discussion and anxiety in the hospital were extremely high and I recall that some of my social work colleagues who became aware of it, felt deeply upset at how it was being managed and the impact of that on grieving parents. There were concerns as to how the body should be managed for instance. This was in 1992 I believe. It was reported in the press.

22. I do recall attending a conference in Liverpool. From the date quoted to me, it must have been very soon after taking up my post in Yorkhill. I am sorry to say I remember nothing of the content but do remember I visited the cathedral and that is the only reason I can confirm being there. Soon after starting work at Yorkhill hospital, Dr Hann made me aware of a haemophilia social work group run under the banner of BASW which is the British Association of Social Workers. It was a special interest group which held independent meetings but which also got together at these family conferences. I can't recall a homoeopathy agenda for the above. It would have been the case that parents and I would have attended different sessions and my time would have been spent in the social work group or a variety of workshops with people from all over the country, some parents, some professionals from health and some adult patients. This was also a time when haemophilia and the impact of caring for a child with a bleeding disorder was new to me.

23. I do not remember anything about a meeting being held at Edinburgh Royal Infirmary or indeed in Edinburgh in December 1984. I am certain that I did not attend and I certainly do not remember any patients or families discussing this meeting. I do remember a meeting which was led by Dr Hann at Yorkhill Hospital, Glasgow although I cannot say when that was. As far as I recall Dr Hann was not at Yorkhill for that long so obviously it was during his short period there. This meeting was attended by parents of haemophilia patients and Dr Hann was advising them of safeguards in respect of HIV.

Statement of Truth

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

Signed 

Date 16 June 2011