

DRAFT – CONFIDENTIAL

PENROSE INQUIRY PROFESSOR CHARLES FORBES – REQUEST FOR WITNESS STATEMENT IN RELATION TO TOPICS B5 & C5(a)

1. I started to work with haemophiliacs in 1965 in the Royal Infirmary in Glasgow, having spent the previous year in East Africa working with Professor A S Douglas who was the Haemophilia Director in Glasgow at that time. I have been asked to make comments from 1971 until 1987 which was a time of great change in haemophilia care with the development and knowledge of both HIV infection and the consequences of Hepatitis C as it became known.
2. At that time the usual policy for haemophilic bleeding was the use of pooled cryoprecipitate. The amount given depended on the severity of the disease in the individual patient and also the type of procedure that was required or the amount of trauma that had been given to the patient.
3. I think at this time we were all aware of the potential problems of all material of blood origin being given to individuals and we did monitor them for changes in liver function tests which at that time was probably the best and only available test. In particular changes in liver enzymes were a good indicator of infection. We quite rapidly became aware that there were probably different types of Hepatitis. A short incubation Hepatitis and a longer incubation and certainly some in between. We were also aware that the chances of developing Hepatitis were lower with locally harvested cryoprecipitates as opposed to concentrates which were made with indeterminate but huge numbers of patients' plasma being pooled together. So generally we tended to favour the use of cryoprecipitate and that continued for many years.
4. We were also very aware of the possibility of using DDAVP in patients with mild disease who were having small traumas or small surgery. This we widely accepted, and was really very successful for a day or two's treatment only, for example one or two teeth or a very small procedure. During this time we also became aware of the other long term implications of DDAVP particularly with fluid and electrolyte retention so it was used with some caution.

5. I think very early on in the progress of the virus story we became aware that AIDS was a blood borne disease probably transmitted by Factor VIII perhaps more often by concentrates than cryoprecipitate. This advice was given to individual patients but as most of the patients were getting cryoprecipitate the question of concentrate therapy arose only infrequently and patients were told about the implications particularly with regard to HIV infection. The end result of course was that we tended to favour the use of cryoprecipitate and that is what our policy was. I think the patients agreed to this and many continued to use the more awkward administration of cryoprecipitate rather than concentrate.
6. Against this background we became aware that the HTLV-III virus was transmitting the disease in our patients. It was with some excitement that we heard that heat treatment of the plasma was a possibility and the date of this was 1984. There was however a lot of concern about how effective this was and indeed one of the early heat treated concentrates clearly had transmitted the virus and that set us all back and it took some time to return to a degree of confidence in the heat treatment process.
7. Despite the fact that we guessed that the virus was transmitted in blood products we did not have any test for the virus itself and it was therefore decided that we should collect samples from patients with a view to storing them until a test became available. This happened very slowly over several years and it was through our association with Dr Mads Melbye that we got access to early testing on special samples. It was by doing this that we were able to show that many of the patients were already positive at the time the test came on stream.
8. The initial samples were taken over a period of several years. As I say, these tests were carried out as a special favour by Dr Mads Melbye, I think in his laboratory in Denmark. Thereafter our local virologist (Dr Eddie Follett) at Ruchill Hospital had set up a laboratory in which he could do the test and thereafter they were routinely done there by him and his colleagues.

9. The next question that you ask about is did the patients get told they were being tested, and I think the answer is a changing one. From the early days in 1980 or so until the tests became routinely acceptable they were probably not told much about it. I don't think that we actually asked for consent for the samples to be specifically tested but as in all these areas things tighten up and then consent was asked for and eventually (informed consent) written. You ask specifically if consent and testing changed between 1984 and 1987 and the answer to that is of course it did. By 1987 specific consent was asked for. Often before that it was not. It was a gradual process which came in. I will go onto the next part which is communication of results and implications of diagnosis.
10. We always had a very open policy about informing patients of the results. With regard to this particular test we did this in association with a session in which they were told the result but also told of the implications of what it meant as far as we knew at that time. The usual way this was done was to invite the patient to have a routine review to answer their questions, of which there were usually many, with the best information we had at that time.
11. The samples were taken, sent off (after local storage) to Dr Follett, and the results were then given to the patients on a return appointment usually a week or two weeks thereafter. As you can imagine this was a very emotional time and the only thing that we could do was to tell the patients in as kind a way as possible that the test was positive and that they might well develop symptoms of AIDS.
12. The information we had wasn't all that wonderful or extensive but there was a very active grapevine and most of the patients and their relatives knew well what the end result might be. At the time we had no specific treatments but these evolved quite rapidly particularly anti-fungals and general supportive measures to keep their immunity high. In addition we attempted to give the patients as much other support as possible in particular those with children and those who were married with a stable sexual partner.

13. It was at this time we employed Mrs Patricia Wilkie who was a wonderful addition to our staff due to her long association with different counselling situations. Many other problems became apparent and we dealt with them on an ad-hoc basis, in particular the question of sexual partners and wives, and also the problem of children who had become positive - although they were usually dealt with at Yorkhill. There is no doubt that a lot of time and effort was put into trying to do this correctly and I think we were really quite successful.

Meeting of Haemophilia Patients in Edinburgh 19 December 1984

14. I think some of these questions probably should be asked of Dr Ludlam who organised the meeting in Edinburgh on 19 December 1984. It was to inform a group of patients from Edinburgh about what was happening with the virus and the implications thereof. I really don't know why I was invited to go but I was, and invited to chair the meeting. Initially I thought it was to keep order but it was a very productive meeting and a very good audience who were by this time quite well informed so it was an open discussion in front of all of the people who came.
15. From memory I think probably about 20 people attended but Dr Ludlam will have whatever minutes he kept of the meeting. I don't know that and I have never seen minutes.
16. There was no agenda set in advance, and the idea was that we would respond to questions as and when they arose. I presume that Dr Ludlam was involved in the decision to give the information. I don't know how many people were actually invited but it was a very good evening, very good meeting in terms of educating patients and no particular emotion surfaced.
17. With regard to where the meeting was I have no recollection. I think it may have been in the Royal Infirmary at Edinburgh but it was done in a lecture theatre situation in which the main speakers were Dr Ludlam and staff, and it went on for a couple of hours. I don't remember actually speaking except to introduce the speakers and generally talk about the topic.

18. I see from the note that Dr McClelland (who was from BTS) was there but I don't remember what any of them said. From memory I believed that patients had been told about the tests that were done but I don't remember if any of the people at the meeting had not been tested and subsequently wanted to be tested. Most of the patients seemed to know what kind of treatment they had been on and I don't remember that as a particular point of discussion.
19. The patients were quite generally well informed. They were not particularly told that HTLV-III could be a terminal illness although many of them knew of patients who had died, particularly in America. As far as I know there was no discussion about Scottish blood products as opposed to American blood products. In particular I can remember the mood of the meeting and I certainly don't remember any hostility from the audience. I think they were generally shell-shocked at the information that had been given to them.
20. I hope these notes and recollections are accurate. It is quite difficult after 40 odd years to remember the details of what we thought at any one time and certainly it is true that one's memory has not maybe been as good now as it was all these years ago.