

## THE PENROSE INQUIRY

### Witness Statement of DR PATRICIA WILKIE

I, Patricia Wilkie, say as follows:

1. My date of birth is [REDACTED] and I am presently [REDACTED] years old. I live in Woking. I am a social scientist. My qualifications are MA, PhD, FRCR (Hon), FRCG (Hon). My first degree is joint honours in sociology with social and economic history. My PhD examines the social and psychological implications of inherited disease and is from the Department of Psychology at Stirling University.

2. In the early 1980's I lived in Edinburgh, working as a researcher at the University of Edinburgh. From 1982 to 1988 I worked as a research fellow employed by the University of Stirling in conjunction with the University of Glasgow at Glasgow Royal Infirmary (GRI) and carried out two studies:

(i) Investigation into the social and psychological implications of Adult Polycystic Kidney Disease and the implications for counselling.

(ii) Coping strategies of Haemophilia families in the presence of HIV and AIDS and the implications for counselling.

In 1982/1983, as part of the project I started commuting to Glasgow Royal Infirmary from my home in Edinburgh to work with kidney patients.

3. While I was already working in Glasgow, in 1983, Dr Charles Forbes, Consultant Haematologist, contacted me late in 1983 and asked me to work with his haemophilia patients. There was an emerging realisation at this time that it was possible that a new virus, then called HTLV III and later called HIV, might be transmitted through blood and blood products. Dr Forbes had

recently returned from a haemophilia conference in USA where it had been reported that HTLV III had been found in the blood of some patients with haemophilia. Dr Forbes had brought back some testing kits from USA which were not yet licensed, and which could detect the presence of HTLV III in the blood. Dr Forbes had anonymously tested the blood samples of a couple of patients with haemophilia and discovered that both samples were HIV positive. Dr Forbes did not know if the samples belonged to severe or mild haemophiliacs. He had done nothing wrong in testing these samples as at that time there were no specific guidelines in relation to obtaining the consent of patients before testing their blood. I know that the Ethics Committee regulations are much stricter now that they were then. He was very concerned about the results of the tests and I think he stopped testing for ethical reasons.

4. The reason Dr Forbes had contacted me was because he was agitated about the test results. He wanted me to use my skills to help his patients. He wanted me to establish what people with haemophilia knew about HTLV III and if they knew about the existence of the virus and whether the patient thought that they may be affected. Also he wanted me to find out if the patients would like to be tested for the virus if a test was available .

5. I accepted Dr Forbes' offer and generally worked for 3 days with the kidney patients and 2 days with the haemophilia patients. A small research project was set up to establish :

- (i) What did patients know about the genetics of haemophilia?
- (ii) What did patients and their families know about infections and haemophilia (e.g. NonA-Non B hepatitis and HIV)?
- (iii) What could be done about any infections?
- (iv) What treatments did the patients think were available?

Dr Forbes was a very ethical man with far reaching ideas. The fact that he wanted to involve me with his patients showed this. At that time there was very little information about the mortality rates of haemophilia patients. Dr

Forbes wanted to improve this situation so started compiling data. Also working in the department at this time were Dr Gordon Lowe, Sister Ishbel McDougall and a Registrar, Dr Madoc.

6. Not long after I started working for Dr Forbes, a letter was sent by the Haemophilia department, and signed by me to all the patients asking whether they would like to speak to me about issues relating to haemophilia. The letter was in very general terms inviting patients and their families to make an appointment to speak to me about haemophilia, its treatment and any concerns they may have. This was sent around the time when there were lots of lurid headlines in the Press about HIV and AIDS. The newspapers reported cases of haemophiliacs being infected with HIV through blood products. There was a general feeling of fear and panic in relation to HIV and AIDS as so little was known about the virus. As a consequence the general attitude to haemophiliacs at this time was diabolical, both among hospital workers and the general public. Many of the patients I saw were from the east side of Glasgow and hadn't been able to go to school for much of their young lives due to their condition. They had no qualifications so couldn't get good jobs. Manual labour was not possible due to their haemophilia. Many of the patients relied on benefits so life was a struggle. Most of the patients I saw who had severe haemophilia are now dead.

7. Almost all of the 20 or so patients I wrote to agreed to meet me. Glasgow was ahead of its time in taking me on as a counsellor. I think GRI was the first haemophilia unit to employ such a person. My role as a counsellor gradually took over from my role as a researcher. I met the patients both individually and with their partners. I would discuss the implications of testing for HIV with each of the patients. I would discuss the implications of being tested and there being a positive result and the implications of not taking a test. The majority assumed they would be HIV positive. One patient didn't want to know. I was usually present with a clinician when patients were given the results of a test. Often I was the one who told them. The implications of a positive HIV test were discussed including information about the sexual transmission of HIV. Insurance was also discussed and indeed I

tried to persuade the Government to be an underwriter to allow people with haemophilia to get life insurance, albeit at a loaded premium. Confidentiality and who should know about the positive status was also discussed. As was how to tell existing and new partners. I don't remember there being very much treatment available if the result was positive. I think some patients were prescribed with AZT. There was not much information at that time so I got help from the Terence Higgins Trust as well as the gay community in Edinburgh.

8. I was also involved in counselling the patients with regard to their sex lives. The issue was quite sensitive as people with haemophilia may not be sexually active because of their disability but might not want to disclose this. We talked about the risk of transfer of the HIV virus through semen and the importance of using a condom. If the patients didn't want to be tested I advised them it was better to assume they might be HIV positive and always wear a condom.

9. I tried to persuade the haemophilia unit to provide condoms and I wrote to Richard Branson and asked him for a sample. He sent a large suitcase full of condoms! I wanted them to be in the haemophilia treatment room where the patients could help themselves but they were hidden away in a cupboard. This reflects an attitude in the clinical medical world at that time; the attitude towards prevention of infection has now changed.

10. I tried to be available to help the patients as much as possible. They could write to me or phone me at any time via the hospital switchboard. I tried to be as positive as possible and give the families glimmers of hope. I believed that because HIV was a worldwide problem, commercial companies would be working very hard to produce drugs to treat the infection. The Terence Higgins Trust was making huge efforts to raise the profile of HIV and AIDS. Consequently the HIV positive patients from the gay community were obtaining good treatment in the best hospitals in London. In Scotland the haemophilia community was not necessarily getting the best treatment.

Patients tended to put on a brave face and tended to minimise the significance of the problems they faced.

11. At this time compensation was an issue. Patients and their families were struggling financially. I would refer them to the Haemophilia Society to get the Society to lobby for them. I was angry at the Government's attitude to compensation for infected haemophiliacs which was along the lines of "it's not as if they were fit to begin with so they shouldn't get compensation". After hearing that, I wrote a strongly worded letter to the Guardian and it was published the next day.

12. I don't remember whether patients were warned of any risks before being given blood products. I doubt that any patient receiving blood products at that time had received such information. It was a very busy haemophilia unit and most people working in the unit were dealing with the day to day care issues and not considering wider implications. A general assumption not peculiar to GRI nor to haemophilia units was that the patients would not really understand what the risks were even if they had been explained to them. Most patients suspected that the products were not absolutely pure. I would look at patients' records to see which blood products they had received over the years. Some had received only Scottish product but others had received American or Austrian product or porcine factor VIII. Those patients who had travelled were most likely to have received the most commercial product. Because blood was donated as a "gift" in the UK but often paid for in the USA, there was awareness that US blood and blood products might not be as "pure" as Scottish blood. It was generally known that some of the American donors were drug addicts or not in the best health.

13. The HIV virus had a huge impact on the haemophilia population. Before the emergence of the virus, people with haemophilia were beginning to live a more normal life. They were able to obtain better rates of insurance than previously. Patients were beginning to feel that the condition had lost some of its earlier stigma and they felt more able to tell people, including their employers, that they suffered from the condition. The arrival of the HIV virus

changed all this. Patients no longer felt able to divulge that they were suffering from haemophilia. Partly because of the sometimes hysterical press coverage, there was an assumption that if you were a haemophiliac you were likely to have AIDS. Patients were unwilling to go to their GPs even for minor ailments as they feared that the local GP, receptionist, practice nurse etc. might not always treat their personal information as confidential. Another consequence was the reduction in surgical procedures carried out on people with haemophilia. Before the discovery of the HIV virus there were more and more joint replacements being carried out. This stopped as the surgery was very bloody and there were very few surgeons willing to undertake such surgery.

14. There was a lot of fear surrounding HIV and AIDS. Generally those with mild haemophilia who had received very little product and had the lowest risk were the most scared of contracting the virus. As some of the patients became ill from AIDS, the hospital didn't have a policy for dealing with them. The medical profession and other health care professionals had received no training in dealing with AIDS patients. I visited one patient in a general ward in hospital who had to have some molars extracted. He was in a separate room from the ward and all personnel entering the room were covered from head to toe in protective clothing. Everyone in the hospital knew that this patient had some serious, infectious disease. It was grim for these men. The haemophilia unit was better but the general wards were characteristic of hospitals at that time.

15. One young man I used to see died within 9 months of me taking up the post. He knew he was seriously ill and he wanted to die at home. He was a huge Celtic fan and wanted to watch a football match on television at home. A bed was made up for him in the living room but before the end of the match, the man lost consciousness. His parents panicked and phoned for an ambulance. When the ambulance arrived, the parents told the ambulance men that their son had AIDS. The ambulance men then refused to take him. Another ambulance was called and the ambulance men insisted that it was NHS policy to transfer the patient to the nearest hospital. The man's parents

wanted him to be taken to GRI but the ambulance men said they couldn't and took him to a nearby hospital instead. He was resuscitated while in hospital and died there two days later. At the end of their lives these patients were treated like "dirty patients".

16. Another young man I saw who was seventeen years old at the time had a boil on his bottom. The surgical team were very apprehensive about treating him and would only take him at the end of the day's list. Nobody wanted to touch him. When he came back from theatre, he was left lying on his tummy on a flat stretcher with a drain. His bed side table was out of reach and he was given only a plastic cup with a dribble of water. I helped him to drink the water. I pulled the table to be near him but when I came back the next morning to see him, the table had been pushed away. He hadn't been given any breakfast as the staff didn't know which crockery to give him. The young man asked me to bring the telephone to him so he could make a call. I asked the Sister if he could have the telephone but she said he couldn't as he might pass the infection on to other patients through the portable telephone.

17. I was also asked to get involved with a family where 2 brothers, aged 16 and 17 were HIV positive. Their mother was obsessive about hygiene and would pour a great deal of antiseptic down the toilet to prevent the spread of infection. She hadn't been given enough information about the virus and didn't know what to do. I was able to advise her that the antiseptic wouldn't make any difference. The boys' father went to the Daily Record and told them his sons had been infected while being treated at the Sick Kids Hospital in Yorkhill. The hospital was not happy about this. I heard that the Sick Kids thought that the mother needed psychiatric help but I didn't think so. In my opinion she was reacting normally to abnormal circumstances. They were an exceptional family and they coped well.

18. In general I do believe that the haemophilia patients received superb clinical care at that time. Charles Forbes had an exceptionally nice manner. Also, he had the vision of working with a social scientist before other units in the country. I did feel, however, that not many of these patients got treated

with the respect they deserved. There was a tendency for them to be treated as second class citizens by the world outside the hospital.

19. I left the unit in December 1987 and a social worker, Miriam Guthrie took over from me.

20. I am happy for my identifying details to remain in my statement.

*I hope this is helpful*

*Patricia Walker*

*April 15th 2011*