

Witness Name: Alison Richardson

Statement No. 1

Inquiry Reference No P1095JP

THE PENROSE INQUIRY

Witness Statement of ALISON RICHARDSON

I, Alison Richardson, say as follows:

1. My date of birth is [REDACTED] and I am presently [REDACTED] years old. I live in Edinburgh. My qualifications are BA, MPhil (in clinical psychology) and PHD. I retired from work as a clinical psychologist within NHS Lothian in June 2008. I am presently a Director of the Waverley Care Trust and, until August 2010 sat on the Scotland Research Ethics Committee after having been involved in Ethics Committees in Lothian for at least ten years.

2. From 1981 to 1985 I worked as a clinical psychologist in the Learning Disability department of Gogarburn Hospital, Edinburgh. Between 1985 and 1987 I continued to work at Gogarburn Hospital and also worked in the Mental Health department of the Royal Edinburgh Hospital. My work there involved providing psychological input to in and outpatients. In 1987 I took up the post of Principal Clinical Psychologist, (later, Consultant Clinical Psychologist), originally based at the Infectious Diseases Unit at the City Hospital, Edinburgh. That department later moved to the Western General Hospital in Edinburgh. I remained in that post until I retired in 2008. I subsequently also worked at the Spittal Street Centre (which provides a range of services including the Community Drug Problem Service and the Community HIV Team) from about 1994 until 2008, the Department of Genitourinary Medicine ("GUM") at Lauriston Place, Edinburgh from 1987 until 2008 and the Haemophilia department of the Royal Infirmary of Edinburgh from about 1988 until 2008. I was Head of Department for Clinical Psychology, Community Psychiatric Nursing and the Harm Reduction Team. The latter provides Needle Exchange service for Injecting Drug Users (IDUs), training for other

organisations and a testing service for at risk gay men. From 1994, I, and the rest of my department were involved with those who were at risk of HIV infection, who had acquired HIV and, latterly, those who were positive for the Hepatitis C virus. These included gay and bisexual men, Injecting Drug users (IDUs) and those who had acquired the virus through blood products (though I was the only member of the team who saw the latter regularly).

3. In about 1985 I started to see a trickle of patients in connection with the Human Immunodeficiency Virus (HIV) at the Royal Edinburgh Hospital. At that time it was termed HTLV3, rather than HIV. Initially the patients were people who were AIDS phobic, i.e. in an anxiety state about having or acquiring AIDS. I had a trainee psychologist working with me at the time, Nigel North, who had worked with HIV positive patients at St Mary's Hospital in London, and he told me about Dr Ray Brettle, Consultant Physician in the Infectious Diseases Unit at the City Hospital in Edinburgh and a GP who had taken a special interest in the drug users and the outbreak of the Hepatitis B virus which had occurred a few years earlier. These two doctors were warning everyone that HIV was going to be a problem. Dr Ray Brettle had been in the USA and he came back very concerned about HIV. Dr Brettle talked to many other doctors about the virus and he spoke to the Virology Laboratory at Edinburgh Royal Infirmary about it. The Laboratory was more interested in the virus than the clinical doctors seemed to be. Few of the clinicians seemed to be concerned that HIV would be a problem here. These concerned doctors were told that they were scaremongering.

4. Sometime in 1986, Nigel North and I went to see Dr Brettle and he sat us down and talked to us about HIV for about two or three hours. He told us what was then known about it and the numbers of people (mainly drug users) who were infected. At the end of our meeting he told me that there would be money in it for psychology if I was interested in getting into this area. I returned to my boss at the Royal Edinburgh Hospital and asked him if there was money for psychology in respect of HIV. My boss said that he did not know anything about the virus and then he started to investigate it. I think that this led to the post, detailed in paragraph 5 below, being created.

5. A short time later, in 1986, I saw a job advertised for a psychologist working with people with HIV. I applied for the job and was successful. I started this post in September 1987. I was employed by, what was then, Lothian Health Board and it involved taking referrals from the GUM department of Edinburgh Royal Infirmary and from the Infectious Diseases Unit at the City Hospital. There was huge rivalry between the two in respect of who was going to be the main department delivering care for those with HIV and I was effectively stuck in the middle of the two. The GUM department dealt with the gay men who had acquired the virus and the Infectious Diseases Unit dealt mainly with the infected drug users. For the first year I had no office and no administration staff. I was parked in a lonely house in Morningside Place in an old Royal Edinburgh Hospital building. I saw patients there and at the GUM department (of Edinburgh Royal Infirmary) and at the City Hospital. My patients were mainly drug users and homosexual men.

6. During my work, in about 1986 or 1987, I became aware that people with haemophilia had also acquired HIV. Quite soon after September 1987, I went to see Dr Christopher Ludlam, Consultant Haematologist, and told him that I was a psychologist working with patients with HIV. I told Dr Ludlam that I would be happy to do whatever I could to help him with the management of his patients. My recollection is that Dr Ludlam was not very welcoming, and, in retrospect, was probably and understandably worried about confidentiality issues. Interestingly, his recollection is that he was on my interview panel and knew exactly who I was, which illustrates the difficulty in recalling events from over twenty years ago. I recollect him telling me that his department did not need help and that they had enough staff to assist with this. They had a good social worker on the team there called Geraldine Brown. I think Dr Ludlam felt that they were doing a good job without needing any more help. Towards the end of 1987, Dr Ludlam told me that I could come and sit in on the haematology weekly team meetings. I am not very sure why he changed his mind about my involvement. Looking back on it and from speculation only, I think that when I first approached him it was still a very uncertain and difficult time for the department and for Dr Ludlam in particular with many dilemmas to

be handled. I probably did not understand the complexities of it, at that time. His first reaction to my offer of help may have been a knee jerk one as he did not know anything about me. Perhaps, after I left, Dr Ludlam thought about it a bit more and he may have spoken to George Masterton, the psychiatrist in charge of Psychological Medicine at Edinburgh Royal Infirmary, who already provided input to the Haemophilia Centre. George Masterton knew me well. At these meetings every Tuesday we sat around and mainly, but not entirely, discussed those patients who were infected with HIV. Looking back at the article printed in the Medical Research Council News in 1990, No. 48, there was a reported number of 32 haemophiliac patients exposed to the infected batch of factor VIII, of whom eighteen developed antibodies to HIV. In the Scottish Centre for Infection and Environmental Health ("SCIEH") report of 1994, it was reported that 22 people had been infected in the Lothians, through blood products, nine of whom had died by 1994. By this time, most if not all the haemophilia patients, who were HIV positive, knew of their diagnosis so we mainly discussed how they and their families were managing with this disease which we, and they, thought would very likely kill them. We discussed a number of dilemmas. I remember best the dilemma about a person with haemophilia who was under sixteen years old. My impression was that this person was among an initial group who had been tested for HIV without his consent or his parents' consent as part of a test of the HIV test itself. [see paragraph 7 below]. I remember debating over and over again, do we tell the child, his parents or do nothing. I think Dr Ludlam's view was to keep trying to persuade them to have the test openly. I think that eventually, a few years later when the individual was 19 years old, he was tested for HIV. I subsequently saw this person, for treatment, many years later

7. I know from what I have read in the report by Chris Bennett and Andrew Pettigrew, "Waiting for AIDS: the story of HIV infection in Lothian", a copy of which I have produced [WIT.001.1029] that in about 1984 Dr Ludlam volunteered some blood samples to a Haematologist in Middlesex. This Haematologist was experimenting with a screening test for HIV – see [WIT.001.1065 and WIT.001.1066]. Dr Ludlam sent this Haematologist some blood samples from some of his patients for him to use as part of this test. I

think that Dr Ludlam fully expected the results of his samples to be negative. Once I started working with the Haemophilia Unit, I repeatedly heard the mantra that "Scotland was self sufficient in Blood Products". I surmise from the subsequent events, that Dr Ludlam must have sent the samples with the ability to identify the samples to individuals. This would not be passed by an Ethics committee now, but that is being wise after the event. I am sure, to Dr Ludlam's utter horror the results of some of these samples came back positive for HIV. This put Dr Ludlam between a rock and a hard place. I assume that he had not obtained the consent of any of his patients to use their blood samples for this test. At that time there was much less concern about informed consent for research studies using stored blood samples which had been obtained for other purposes. It is perfectly possible that blanket consent had been obtained for the use of blood obtained for clinical purposes to be used for research purposes. Indeed, this seems very likely, though I have no certain knowledge of this.

8. Most of the patients I subsequently saw, after being referred to me by Dr Ludlam, recall being asked to come to an urgent meeting with Dr Ludlam. I am not exactly sure when this meeting was but I presume it was after these blood test results came back in about 1985. I think Dr Ludlam invited all the patients with haemophilia and not just those who were infected with HIV. Dr Ludlam wanted to warn them about HIV in the blood supply. I think that Dr Ludlam intended to persuade all the people with haemophilia to have a test for HIV. I was not present at that meeting, since this was before I had taken up my post. From what I have heard from the patients I spoke to subsequently, Dr Ludlam told them that some people with haemophilia in Scotland were infected with HIV. Two of my patients said that they were told at the meeting to use condoms when having sexual intercourse with their wives. From what I have heard from these two patients, the general feeling leaving that meeting was "well, thank goodness, I don't have it, because if I had, he would have told me." So, they left the meeting thinking that they did not have HIV. Dr Ludlam is a great scientist, a great humanitarian but not necessarily a good communicator. I do not think he would have handled the meeting well. I think he will have talked round and round the subject without

making it clear what was going on. The big problem was those patients who would not be tested; I think there were about five of them. Again, I would assume, he was doing his very best to sort out a very difficult problem. My view would be that his encouragement to the haemophiliacs to have the test was the right thing to do. I know that some of the patients with haemophilia, when they found out that HIV was in the blood supply, stopped using Factor VIII products.

9. I think that a GP, with a drug using population, had done the same thing as Dr Ludlam i.e. sent some samples to the Haematologist in Middlesex to be tested for the HIV. I think this was done at the same time as Dr Ludlam sent his samples in 1985. However, this is again, guesswork. I think that they planned to compare the drug users' stored blood with the haemophilia stored blood. Certainly one man, maybe more than one, was referred to me by a GP so that I could steer him towards having a test for HIV as it was known that he was HIV positive, but the patient himself did not know that he was HIV positive. I doubt that this was specifically mentioned in the referral document but was probably mentioned in conversation. I saw other people, for example, drug users where their doctors knew that they were infected with HIV but they were refusing the test. These doctors were in the same position as Dr Ludlam. It was very important from the point of view of preventing the spread of infection that these people knew of their diagnosis, as without knowing this they would not know to take precautions.

10. For years the GUM department at Edinburgh Royal Infirmary carried out anonymous testing. I can't remember when this testing was started. I think it is still carried out in Glasgow, but was stopped in Edinburgh some years ago. People gave their consent, when giving blood samples for other reasons, for their blood also to be tested for HIV. This testing was run by Health Protection Scotland. (previously SCIEH). Many people refused the test. Every year they knew the percentage of people going through the department who were HIV positive, what proportion knew of their diagnosis and what proportion were refusing to have the test, but were HIV positive. Many people, who were, and are, clearly at risk, refuse to have an open HIV

test, perhaps out of fear, or not wanting to change their lifestyle. These are huge psychological issues for people and ones that I was very much involved in for many years.

11. In about 1987 or 1988 Dr Ludlam gradually started referring people to me. By the end of 1988 I was seeing some people with haemophilia who were infected with HIV. It was generally acknowledged by everyone that those patients who were infected with HIV were also infected with Non-A Non-B Hepatitis. I paid very little attention to the Non-A Non-B Hepatitis virus (subsequently hepatitis C) as HIV was such a big thing at that time. I don't think that I ever discussed Non-A Non-B Hepatitis with any of the patients. Initially, out of the eleven patients I knew about and had contact with, at least seven decided to meet with us in the group. The group was carried out by Geraldine Brown and me. All 11 patients knew that they had HIV. I think, four or five patients did not want any psychological help. One patient was a child whose mother did not want to know and one patient I met years later after he was referred to me either by the Haemophilia Department or the Infectious Diseases Unit. Eventually I did see all 11 of them, nine of them died, eight of AIDS. I got on with most of them really well. They were people who had suffered a great deal throughout their lives, had seen the introduction of treatment which would help them, alleviate their pain, alleviate their suffering and allow them have more normal lives, only to find that it had introduced a potentially fatal disease.

12. I saw some individually and some in groups. In about August 1989 I started a group with Geraldine Brown for those people with haemophilia who were infected with HIV and then we started a group for their relatives. The patients were all extraordinary people, having had difficult lives, with many painful and long admissions from childhood. Most of them were not ill at that time. We discussed many topics including anger against BTS and Dr Ludlam, suicide, wills, funerals, loved ones watching them all the time for symptoms, being more irritable with family, sexual anxieties and alcohol problems. Many of them believed that they had been used as guinea pigs. One man came to a group meeting a couple of times but then stopped coming as it was making

him feel more anxious. One patient, in particular, was the angriest. He had decided to kill himself. He hated homosexual people and drug users as he felt that they had given him the virus. One patient was absolutely terrified until the week before he died. His wife was terrified too. Three patients had severe alcohol problems although they had had them before their infection. I saw just one woman and saw her individually. She had had a blood transfusion on the birth of her second child and I think that she was the only patient I saw who had acquired HIV from a blood transfusion. She died horribly. She went blind. She acquired the cytomegalovirus. She would not take any painkillers or be sedated. She was barely able to communicate. The groups lasted one or two years. Two brothers and their nephew who attended became ill. The membership got smaller and smaller and they ended up watching each other die.

13. I kept on seeing a couple of people with haemophilia, out of the eleven I initially saw, as they were well enough to continue and wished to do so. The busiest period working with the patients with haemophilia was between 1985 and 1992. One of those people was very angry and needed to blame someone for what had happened to him. I kept seeing him until about 2006. A lot of those with haemophilia were very angry about placing their partners at risk as they did not know about their diagnosis.

14. I also, later saw a few haemophiliacs without HIV, but with HCV. One blamed his medical treatment for his infection and the other absolutely does not and has nothing but gratitude for his treatment.

15. In about 1988 or 1989 or maybe earlier, Dr Ludlam or the Edinburgh Haemophilia Centre produced some guidelines - "Guidelines for counselling pre- and post HIV testing for patients receiving or likely to receive factor concentrate and cryoprecipitate" [WIT.001.1150]. I think that these guidelines may have been issued earlier than 1988 or 1989 as, if I had been around at the time, I would have suggested other matters be added to these guidelines. In the first paragraph of these guidelines it states "Some people have been

tested in the past without consent.” The discussions amongst the doctors never ended. They were always discussing it and worrying about it.

16. At the time those patients with haemophilia were found to be infected with HIV in the 1980s, mistakes may have been made, none intentional in my view. It was all so new for everyone. I think the medical staff tried to get it right but did not manage it particularly well, but, again, that is with the benefit of hindsight. For example, patients report that those who were found to be HIV positive had a “high risk” sticker put on the front of those patients’ notes. The patients felt that anyone could see it. I do not remember having seen that.

17. In the early days, i.e. the 1980s to the 1990s, people infected with HIV did often die. Only later did it become apparent that some people’s immune systems “managed” and they remained unaffected by it, though remaining HIV positive. These people are few and far between and I do not know of anyone infected through blood products who fell into this category. In about 1989 or 1990 AZT was prescribed. It gave you an extra year but, as everyone eventually died, many people thought that AZT killed you. AZT was only given to the sickest people and had a lot of side effects. Two years later in 1992, ddI (Videx, also known as didanosine) and ddC (Hivid, also known as zalcitabine) started to be used. The big breakthrough came in 1996 by which time a lot of people with haemophilia had died.

18. I know that Anne Stallard was a psychologist who carried out similar type of work in Glasgow and I think that there was a psychologist in Dundee although I cannot remember her name. There were two district nurses in Edinburgh who were great. They used to go to people’s houses when they were dying at home and put up infusions.

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

Statement of Truth

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

Signed *Mr Richard*

Dated *15th October 2010*