

**Professor Ian Hann Response to further questions from Penrose Inquiry  
Dated 13/04/2011**

I would like to respond to the Inquiry's letter dated 31/3/11 relating to Topic B5

**Information about the risk of HIV infection**

***1. When the possibility that AIDS was a blood borne disease which affected haemophiliacs became apparent (around December 1982) did Professor Hann discuss the implications with his patients (or their parents) before continuing to use factor concentrate therapy?***

1.1 I cannot recall the detail of discussions with regard to risks of therapy. The situation at Yorkhill was that we had a completely open approach and questions could and were asked on many topics in the day care area, in the clinics which Dr Pettigrew and I set up for this purpose and clinical review for the first time, and in the patient/parent support groups that we set up for the first time. The latter were supported with variable attendance but were well advertised and open to all.

1.2 I have a vague recollection that the theme of at least one of these support groups was HIV/AIDS and other virus risks and that the ERI / GRI consultants arranged an open meeting for persons with haemophilia to discuss this topic, although I may be wrong in that memory of distant events.

1.3 Throughout, we encouraged strong links with the Haemophilia Society of which I became a medical advisor, through Mr Dolan and others. The Society was and is dedicated to providing information on risks and other matters to the community over many decades.

1.4 When I took over, most of the patients had of course already been established on home therapy. Those few that were diagnosed anew had a full discussion of the disorder and its treatment. It should be remembered that Hepatitis C had not been described at the time and that the natural history of the non-A non-B hepatitis in these patients was uncertain. We would not have used the term hepatitis C.

1.5 There were many discussions with patients following the initial descriptions of the HIV transmission risks and we would have explained what we knew at the time. We would never have knowingly exposed patients to increased risk.

**2. Did Professor Hann consider switching his patients back to cryoprecipitate? Did he discuss that option with his patients (or their parents)?**

2.1 Following the description of HIV transmission risks we thoroughly reviewed the approach to therapy in individual patients and made absolutely sure that those who did not require factor concentrate therapy eg mild/moderate haemophiliacs, were not exposed.

2.2 We considered turning back the clock to plasma – (cryo/FFP) based therapies where it was feasible, but of course this would have meant abandoning home therapy and avoiding operations in the majority of cases. I think that some patients may have switched to cryoprecipitate with all its deficiencies of reactions, uncertain dosage, problems of storage and infusion.

2.3 Such strategies were certainly brought up by parents along with more use of eg DDAVP and we would not have resisted this change.

2.4 All therapeutic decisions were approached in a non-paternalistic way, and I believe that the Haemophilia Society supported our type of approach.

#### **Testing and Consent (HIV)**

**3 When did Professor Hann start testing his patients for HTLV-III?**

3.1 We started testing for HTLVIII when a test became available and when its reliability had improved. I do not recall when that was but I think that it was through SNBTS and that there were several attempts at tests that were not satisfactory prior to that.

**4. In what circumstances were these blood tests carried out? When were blood samples taken from his patients? Were the blood samples taken with the intention of testing for HTLV-III? Who carried out the tests?**

4.1 I cannot recall the detail of testing. It was probably a mixture of 'look-back' and then actual testing in real time. I think that testing was done at or via SNBTS but this may not be correct.

**5. *Did Professor Hann tell his patients that HTLV-III tests were being carried out? Did he obtain consent from his patients (or their parents) before carrying out the HTLV-III tests?***

5.1 The question of consent is mentioned here and in many sections of the report. I would like to make it crystal clear that both with the persons with haemophilia and the majority of my patients who were those with cancer, solid tumours, leukaemia and other blood disorders, the whole ethos of the department was open and non paternalistic. Consent in this era was not usually written as we believed that it was a process whereby information was supplied on an open, transparent and regular basis as things changed clinically and scientifically.

5.2 That approach had changed by the late 1980's/early 1990's through moves to obtain written consent and much more emphasis on comprehensive written information, which I helped to instigate at Great Ormond Street Children's Hospital. There was never any intention to hide anything from anyone and we all did our best for our patients.

5.3 I was the consultant and director and take full responsibility for all clinical events, but it was not the case that I was a sole person obtaining consent for testing and the many other issues involved.

5.4 As far as I remember, routine testing according to the standard UK guideline of the time was, from my taking up the post, for viruses and hepatitis and my firm belief was that parents were made aware of that. Such testing was carried out at least twice a year and parents and children had every opportunity to ask what tests were for, and in my experience they usually do. There was no reason for us to conceal these facts. I would be surprised and disappointed if our communication on these issues was not adequate at the time and would have expected that this was a particularly well informed group via the Haemophilia Society newsletters and many other sources. However, I have no doubt that we could have done this better especially if more resources had been identified. The best way to explain this, in my view, is that we learnt a great deal from this

tragic episode, most of us never having been involved in such an event or anything like it previously.

5.5 By the time we reached the 1990's and the discovery of Hepatitis C I was able, as Medical Director at Great Ormond Street Children's Hospital with responsibility for the whole hospital 'look back' and testing and eventually therapy of what we now know to be this disease, to ensure full counselling services before during and after the testing, with ample written, audiovisual and other support through expert trained counselling staff.

5.6 If nothing else, that is what testing for HIV helped us to understand. However, similar challenges will continue to arise eg with prion disease where psychological and personal financial issues are paramount.

**Communication of HIV results and Implications of diagnosis**

**6. *What was Professor Hann's practice in relation to telling his patients (or their parents) of positive test results? Did Professor Hann inform his patients (or their parents) immediately upon receiving their results?***

6.1 Parents would not have been informed immediately upon test positivity because, certainly in that era, false positive results were not uncommon and in fact occurred in my patients. Distributing that information would, in my view, have caused great unnecessary anxiety. The information was conveyed to parents as soon as the confirmatory tests became available or shortly thereafter.

**7. *At the UK Haemophilia Reference Directors' meeting on 10 December 1984 [SNF.001.3850] there was a long discussion on whether persons found to be HTLV-III positive should be told. We note that Professor Hann did not attend that meeting. Was he aware of what was discussed in relation to informing patients of test results?***

7.1 I am not aware of exactly what was discussed at the Reference Directors' meeting on 10/12/1984, but I was fully aware of the many discussions going on around the UK with regard to the issue of withholding test information. This is a very important point because it relates to the then very thorny issue of why the testing was done.

- 7.2 It was a thorny issue for many reasons. There was, in my view and that of many others, an absolute imperative to ensure that we picked up any other infected batches with prospective testing. There was a need for family counselling with regard to hygiene, sexual activity etc (we were not in the position of having firm information on infectivity etc) and there was a need to know eg in children why they were ill at any point and what to look for and how to treat / manage it. We would have been acting blindfolded if we had not known and would have been putting lives at risk due to failure to institute prompt therapy.
- 7.3 There was an issue over lack of specific antiviral therapy which became far less relevant as time went by of course. With regard to doing the test and not informing people of the result - that at the time was a thorny moral and ethical issue and I was and am very strongly of the belief that this is rarely if ever justifiable to adopt secrecy.
- 7.4 There was also the possibility on the horizon of antiviral therapies. In my view, if such testing is done and absolute confidentiality is maintained, then testing was essential and if testing were done then I could see no justification for secrecy.
- 7.5 I can remember occasions when attempts to breach that confidentiality were made and we all fought very hard to block that activity, with complete success as far as I know. I am aware that we did not manage this as well as should have been the case (bearing in mind that we had for instance very limited counselling services in the era) and I do remember one family initially feeling that they should not have been told, although I would imagine that with time they would be aware that that stance with regard to a child was untenable in the longer term. However, this attitude was fully understandable in the circumstances as these patients were being ostracised in schools and elsewhere.
- 7.6 By way of example as to attempts to breach confidentiality, I had contact from dentists and other health care professionals wanting to know patients' HIV status. I always refused to disclose this. There was a great deal of uncertainty with regard to the patients' infectivity of others and I recall that some children in Scotland were unable to attend school because of actions of other parents. I believe that there were contacts from teachers, dentists and possibly GP's but I have no detailed recollection apart from one major incident.

7.7 The major incident I refer to was when a senior Head of Public Health for one of the Scottish Areas demanded to know the HTLVIII positive names for that area so that he could give the names to dentists and other HCP's. We had a very unpleasant exchange when I repeatedly refused under duress to disclose these. As a result he reported me to the senior doctors in the CMO's office in Edinburgh. I was contacted by, I think, Dr McIntyre who said that they were considering disciplinary action against me. I was asked to see him and did so and defended my position on behalf of the patients. He said that they would reconsider if I agreed to a 'Tumour Registry' Epidemiology type of approach ie TOTALLY anonymised TOTALLY confidential numbers versus large areas, with a protocol specifying the issues to be addressed.

7.8 I do not recall any further contact on this issue but there should be some written communication available which I did not retain personally.

**8. *What arrangements were made for patients (or their parents) to be told of positive test results?***

8.1 I do not recall what specific arrangements were made for informing parents of test results. This would usually have taken place in the day care area as the Hospital did not have a dedicated Haemophilia Centre and we did not have dedicated counselling rooms or counsellors. It may also have occurred at clinic appointments.

8.2 The information would normally have been through the long-serving excellent staff member Dr Pettigrew in whom I had the utmost confidence. During my 40 years in medicine she would be amongst the most sensitive, caring, thoughtful, intelligent and clinically skilled of doctors, who also happened to know the families very well and provided them with first-rate holistic care which I was eventually able to replicate some years after taking up my post at Great Ormond Street Children's Hospital.

8.3 It is important that the Inquiry understands that although imparting this information in a caring way at the outset is vital, this is only the start of a very long process of contacts over a large number of years.

**9. *What did Professor Hann tell his patients (or their parents) about HTLV-III?***

9.1 I do not have details of the information provided to patients in written and verbal form at the time. As stated above, the intention was always to be open and non-paternalistic and to provide as much relevant information as was needed and asked for.

9.2 My memory of this population is that they were not backward in coming forward on multiple occasions with enquiries and questions and I do not recall any complaints that we had failed to discuss issues with them through clinics, day care visits, group meetings and their information from other organisations and especially the Haemophilia Society.

9.3 We learnt from this era that more written and audiovisual information is required in such circumstances and I am sure that that would have helped at the time.