

Written Response by Dr A F Pettigrew to Questions from Penrose enquiry

1. I started working in the Haematology Unit of Yorkhill Hospital as a Part Time Clinical Assistant in May 1980. At that time, there were a number of children already established on Prophylactic Home Treatment. I cannot remember the exact number of these children but there were approximately 6 at that time. These children received regular, I think twice weekly, Factor V111 concentrate injections as well as additional treatment given by the parent as required for acute bleeding episodes.

Dr Willoughby had introduced home therapy initially in 2 boys with Haemophilia who, I had been told by Dr. Willoughby and other clinicians at Yorkhill, had been regular attendees at casualty -up to 2-3 times a day- and frequently required admission because of bleeding episodes and after commencing home therapy, their rate of attendance and admissions had fallen dramatically. It was my impression that Dr. Willoughby had introduced home therapy and Prophylactic treatment in an attempt to give not only the children but their families as normal a life as possible.

As far as I recall, the children on home treatment received both commercial Factor V111 and also SNBTS Factor V111 depending on what was available.

I had been told by Dr. Willoughby that commercial Factor V111 was used to ensure a reliable supply of Factor V111 concentrate as, at that time, Scotland was not self sufficient in Factor V111 concentrate and in order to carry out a prophylactic care programme, there had to be a reliable source of Factor V111. Cryoprecipitate was impracticable for home treatment use.

As far as I recall, children who were not on Home treatment would receive either cryoprecipitate or Factor V 111 concentrate-SNBTS or commercial depending on supplies. Cryoprecipitate would usually be given to the younger children and to mildly affected Haemophiliacs. DDAVP could be considered for mildly affected children with Haemophilia A particularly for example pre dental treatment.

2. The age of transfer to the adult centre varied. The less severely affected and thus less frequent attendees were transferred around 15-16 yrs of age. The more severely affected boys transferred around age 16 to 17 years or even older depending on physical size, maturity and parental preference.

3. The initial decision to use commercial Factor V111 was taken by Dr. Willoughby before I arrived at York hill for, I presume, the reason outlined in answer 1. I have no recollection of either attending the meeting thirty years ago on the 31st Jan 1981 or what was discussed at that meeting.

4. The decision to use commercial factor V111 was taken by Dr. Willoughby.

A F Pettigrew
25/1/11

5. As far as I recall, the commercial Factor V111 was ordered by the haematology department usually by the Senior chief Technician and I think he dealt directly with the Pharmaceutical Company.
6. I do not know why Armour Factor V111 was chosen in particular. This was already in use when I took up my post.
7. A number of parents had already been trained to administer Factor V111 to their children before I took up my post at York hill and during my years there, I, along with the Haemophilia Nurse Specialist and occasionally other Haematology medical Staff, was involved in training parents to administer Factor V111 and factor 1X concentrate.
8. I believe the amount of commercial Factor V111 used fell during 1982/83 as there was greater availability of SNBTS Factor V111 concentrate as Scotland moved toward self sufficiency.
9. As far as I am aware, Dr Willoughby left Yorkhill to take up a position in Perth Australia as he felt this offered a better quality of life for himself and his family.
10. I have no recollection of the meeting in Stirling in 1982.
As far as I recall, I would have been first aware of the possibility of that AIDS was caused by an agent transmitted by blood and blood products in 1983.
11. I do remember visiting the PFC at Ellen Glen with the Haemophilia nurse Specialist and being given a tour of the PFC to see first hand how factor concentrates were produced. I think it was at the time of introduction of heat treatment as this was discussed. I may have given a presentation to the staff on Haemophilia but I do not remember this being filmed nor do I have a copy of such a film.
12. I cannot remember the exact number of children who were first found to be positive for "HTLV3" as it was termed then but I think it was about 8-10, some of whom had already transferred to the adult unit and one had moved to a different part of the country. These results were received in a letter to Dr Hann from Dr Follett the virologist. He had carried out initial testing retrospectively on stored serum.
13. The initial testing was carried out retrospectively on stored serum and I do not know who initiated this testing. The sera had been obtained from specimens taken at regular intervals from patients with Haemophilia to test for Hepatitis B. We would normally have advised parents why bloods were being taken. I have no recollection of parents or children being told that the initial testing was being carried out retrospectively on stored serum. Following receipt of initial retrospective results children were retested to confirm the results after discussion with the parents.
14. I cannot explain this discrepancy.

William
27/11

15. When the letter from Dr Follett advising that a number of children had tested positive for the HTLV3 Ab was received by Dr Hann, he advised that the parents should be informed at the soonest opportunity. They were not invited to a special clinic in order to have the discussion. I saw some parents opportunistically in the Day Bed Unit and informed them of the results and discussed with them what was known at that time regarding the implication of a positive test.

There was a regular Haemophilia clinic and some parents may have been informed by me or Dr Hann when attending the clinic and it is possible that more than one were seen at the same clinic.

The Haemophilia Director of the adult unit at the Royal Infirmary was informed of the result for those patients already transferred and I wrote to the consultant responsible for the care of the patient who had moved to another part of the country.

16. At that time, it was custom and practice in Yorkhill to discuss the care, treatment, diagnosis and procedures with parents initially and then usually with the parent's permission, the clinician would explain treatment, diagnosis and procedures in appropriate terms to the children.

This was Pre the Children's Act of 1989 and the Children (Scotland) Act of 1995.

With regards to the results of the HTLV3 testing, we did encourage and indeed advise parents that, particularly in the older children, we should discuss the results with them but not all parents wished us to do so.

17. As far as I recall, the children who tested positive were referred to the Infectious disease Unit-then based in Ruchill Hospital-for advice on management of their HIV. Treatment in general continued at Yorkhill with children also attending clinics at Ruchill.

18. At that time, the only support for patients and families affected by HIV was through organisations relating to the "Gay community" such as the Terence Higgins Trust. Both parents and clinicians did not feel this was appropriate for the children with Haemophilia and their families. A great deal of support and counselling was given by social workers, one lady based in Yorkhill and a gentleman whom, I think, may have been based in Ruchill but was very active in his support for these families. The medical staff in the unit (including myself) and the haemophilia nurse specialist most of whom had built up a close relationship with these families over the years, did their best to provide continuing support and counselling.

19. I am sorry but I do not have a copy of the presentation "Aids and Hepatitis in Haemophilia".

C. J. Hann
25/1/11