

P - AIDS A8 B²³

NORTHERN REGIONAL HAEMOPHILIA SERVICE

NEWCASTLE AREA HEALTH AUTHORITY (TEACHING)
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Ref: PJ/LM

26th May, 1983

Dear Colleague,

AIDS and Haemophilia

I thought I should drop you a note about the present spate of publicity surrounding the acquired immuno deficiency syndrome. As you know, this has been reported chiefly in male homosexuals in the United States and also amongst Haitians, intravenous drug abusers and haemophiliacs. There have been sporadic cases in children. Because of the appearance of the syndrome in haemophiliacs the inference has been drawn that a transmittable agent is at work through blood products, and in particular factor VIII concentrates from the United States.

The transmittable agent is presumed to be a virus and a link has been found with the human T cell leukaemia virus. However it is not yet known whether the presence of HLTV in people with AIDS represents a cause and effect relationship or not; it could simply be there as one of the spectra of opportunistic infections.

AIDS is being monitored very closely in both the United States and the United Kingdom. Last week 14 cases of haemophilia with opportunistic infections had been reported to the Atlanta Centre and one to the Collingdale Centre. The indications for reporting are legion, because nobody quite knows what makes up the syndrome. Hence the documents that need to be filled in include all the rarer infectious diseases, all malignancy and all auto immune phenomena. As an example, we had a case of childhood ITP last year in a haemophiliac and information about this has been sent to John Craske who is co ordinating the figures for the Haemophilia Centre Directors.

Of the 14 American cases, one is bisexual and one an intravenous drug abuser. The 12 remaining cases all presented with opportunistic infections and there have been 7 deaths, all associated with pneumocystis carinii pneumonia.

The British case has had two episodes of oral thrush and one episode of orchitis and is getting better. The fact that this adult haemophiliac is said by Collingdale to be a "confirmed" case is, I think, somewhat suspect.

I think three facts need to be borne in mind when we are advising patients:

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- Firstly, there are 12,000 haemophiliacs in the United States and only 14 cases of AIDS, with 7 deaths. There are 4,000 haemophiliacs in the United Kingdom with only one reported case. In neither series of haemophilic patients has ~~Ka~~Kaposi's sarcoma been a feature.
- The incubation period for the transmittable agent in AIDS looks like being around 18 months. If this is true then even if the agent has been recently introduced, one would expect to see many more cases amongst the haemophilic populations most exposed to factor VIII concentrates from the suspect areas. Typical of these populations are those of West Germany attending the Bonn Centre and those attending the major reference centres in the United States.
- Thirdly, the effects of withdrawal of factor VIII concentrate treatment for our haemophiliacs would mean the cessation of home therapy and prophylaxis and the withdrawal of elective surgery. The effects of this are obvious. It is worth noting that both measures were in force in the United States for some time last year but have now been rescinded and patients in both New York and California, where the measures were implemented, are now back on their home therapy programmes and elective surgery has been re-started.

The Haemophilia Reference Centre Directors met in London last week with Peter Hamilton representing Newcastle. At that meeting it was decided that there were no indications for special measures amongst the UK haemophilic population, apart from stressing the need for very small children (under the age of 4) to be treated with cryoprecipitate in preference to factor VIII concentrate wherever possible. As you know this does not represent a change in policy. Naturally careful surveillance of the haemophilic population will continue. I expect that you know that the Haemophilia Society issued a statement about AIDS a couple of weeks ago, but I enclose another copy of this for your files. All our patients should be in the picture but if any specific queries emerge, please do not hesitate to refer them on if you wish.

Kindest regards,

Yours sincerely,

GRO-C

PETER JONES
Director

Enc.

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