

---

# Appendix 31

---

4/S A9.  
11/526/14

# NATIONAL HAEMOPHILIA TREATMENT CENTRE

LÁRIONAD CÓIREÁLA HAEMIFÍLE NA hÉIREANN

## ADULTS

ST. JAMES'S HOSPITAL,  
P.O. Box 580, Dublin 8.  
Telephone (01)757941.

## CHILDREN (UP TO 15 YEARS)

THE NATIONAL CHILDREN'S HOSPITAL,  
Harcourt Street, Dublin 2.  
Telephone (01)752355.

9th August, 1983

Mr. Shay Farrelly,  
Hon. Secretary,  
The Irish Haemophilia Society,  
149, Shantalla Rd.,  
Beaumont,  
Dublin 9

Dear Mr. Farrelly,

Thank you for your letter of 31.5.83. in which you inquire about AIDS. I can assure your Committee that the concern it expresses is shared by the National Haemophilia Treatment Centre.

It would be wise at the outset to separate AIDS from hepatitis. Both the Blood Transfusion Service Board and Commercial products have been associated with hepatitis. All products used in this country are screened for hepatitis B. It should be made clear however that hepatitis may prove yet to be a serious problem - perhaps more serious at least in terms of numbers than AIDS.

A lot of what I wish to say to your Committee is covered in my suggested contribution to your broadsheet. To my knowledge only one definite case of AIDS has been observed in the U.K. and as I put out in the broadsheet haemophilic persons may contract the disease without infusion of concentrates.

The policy of the Directors of the Regional Haemophilia Centres in the U.K. is to allay fears and to continue using all concentrate products both national and commercial until more evidence regarding the incidence in haemophilic subjects and the nature of the condition becomes available.

As you know my policy is to support the Blood Transfusion Service Board production of concentrates. However, I do not believe the issue of AIDS should be used to make injudicious decisions. There are many problems regarding BTSB versus commercial products and AIDS is only one. It must be remembered that BTSB cannot guarantee that its products will not transmit AIDS.

As you can see from my other contribution much thought and effort is going into the problem of AIDS. May I stress the need to ensure that everyone is ultimately assessed throughout the next year or so.

Yours sincerely,

GRO-C

Ian J. Temperley,  
Medical Director

11/526/113

L/S A8/1

**NATIONAL HAEMOPHILIA TREATMENT CENTRE****LÁRIONAD COIREÁLA HAEMIFÍLE NA HÉIREANN**

ADULTS  
ST. JAMES'S HOSPITAL  
P.O. Box 680, Dublin 8.  
Telephone (01)787541.

CHILDREN (UP TO 16 YEARS)  
THE NATIONAL CHILDREN'S HOSPITAL  
Marston Street, Dublin 2.  
Telephone (01)782385.

**AIDS - A MENACE TO HAEMOPHILIACS?**

During the past twelve months Acquired Immodeficiency Syndrome (AIDS) has received much publicity. Most of this is due to its sexual connotations. The relationship with drug addicts, which not so clear-cut, also provides further notoriety and because of the association with intravenous medication brings the subject closer to people with haemophilia who are dependant upon coagulation factor VIII or IX concentrates.

There is no doubt that AIDS is a serious condition which leads to a number of different clinical but biologically interlinked conditions. The basic problem is loss of the immune defence system of the body. The agent which produces this profound change has not been isolated but there is a strong suspicion that it may be a virus. It well may be that prior to affecting the defence mechanism it produces a clinical picture which may be identifiable but not unique. The incubation period may be long perhaps in the region of half a year. It should be emphasized that much of the above is at present conjecture rather than fact.

Information to date suggests that the condition is endemic in Central Africa and Haiti. It is tempting to postulate that the condition originated in Africa spread to Haiti and then to the United States of America. The condition in the U.S. has been most commonly reported in San Francisco, Los Angeles and New York. There are known to be cases in Europe including the United Kingdom.

It is important to realize that the vast proportion of reported cases are non-haemophiliacs. The National Haemophilia Treatment Centre has recently been associated with a study carried out by members of the North Western University, Chicago. Information was received from 29 centres in 15 countries representing 4,310 haemophilic subjects. Despite long exposure only 5 possible cases of AIDS were identified and the Organizer stresses that the word 'possible' must be emphasized. Also, it cannot be assumed that the condition was contracted by intravenous infusion of VIII or IX concentrates.

It would seem therefore from information available that AIDS is rare in haemophilic subjects. Steps are being taken to ensure that this remains the case. Commercial firms who supply Ireland are co-operating fully with the U.S. Food and Drug Administration. Both they and the Blood Transfusion Service Board are taking every appropriate step to ensure the safety of recipients.

1/1526/13

L/S A9/1

**NATIONAL HAEMOPHILIA TREATMENT CENTRE****LÁRIONAD CÓIREÁLA HAEMIFÍLE NA NÉIREANN**

ADULTS  
ST. JAMES'S HOSPITAL,  
P.O. Box 580, Dublin 8.  
Telephone (01)762941.

CHILDREN (UP TO 16 YEARS)  
THE NATIONAL CHILDREN'S HOSPITAL,  
Harcourt Street, Dublin 2.  
Telephone (01)762266.

- 2 -

The collaborative study between the National Haemophilia Treatment Centre and the Northwestern University has already been alluded to. The National Centre is making arrangements with the Committee of Regional Directors of Haemophilia Centres in the U.K. to co-operate in exhaustive studies to ensure Irish haemophiliacs receive immediate benefit of information and research. The Centre is also embarking on its own research programme which will continue throughout 1983-84. All haemophilic subjects attending the National and Regional Centres will receive a thorough clinical and laboratory assessment to exclude the condition.

What then is the advice to haemophilic persons.

1. You have faced the problems of jaundice and hepatitis with courage and understanding. The possible problems of AIDS must be encountered with the same fortitude.
2. Present information suggests that AIDS is rare in people with haemophilia. The benefits of the usual intravenous therapy are too well known to be enumerated. The balance to date therefore falls decisively on the side of continuing treatment as before.
3. Do not hesitate to visit the National and Regional Centres for advice.
4. Please be assiduous in attending the Combined Haemophilia Clinics. Special assessments will be undertaken throughout 1983-84.

GRO-C

Ian J. Tappinley,  
9.8.83.