

The Children's Hospital

Ladywood Middleway, Ladywood, Birmingham B16 8ET
021-454 4851 Ext: 6080

Please reply to: Haematology Dept. Your ref:

Our ref: FGHH/PAM

24th November 1986

Dear Mrs. Currie,

Re: Mrs. GRO-A
GRO-A Leicestershire

Thank you for the concern you have expressed for this family and the difficult problems that they are facing. Dr. Donohue showed us your letter because she felt it more appropriate that we should reply to you. In your letter you touch on the issue of support for haemophiliacs and their families and so we would like to acquaint you with our difficulties in providing counselling support. As you will remember from your past association with the Birmingham Central District Health Authority, The Children's and Queen Elizabeth Hospitals have the Regional Haemophilia Units providing care for some 400-500 patients with bleeding disorders. Amongst these are some 200 severely affected haemophiliacs and of those with severe Factor VIII deficiency (Haemophilia A) approximately 65% (55 adults and 40 children) have contracted the AIDS virus from their treatment. In addition, we have identified some wives who carry the virus.

The staff that we have on these Units to treat the medical aspects of the haemophilia before the advent of AIDS were stretched. Despite this we have tried to provide as much advice and counselling as possible to our patients and their relatives. These demands have and are continuing to increase as the patients and their families become increasingly aware of the consequences of the AIDS virus infection. The time available for counselling, we admit, is totally inadequate and we are constantly aware of our inability to adequately follow-up patients in this regard. As some leave the clinic we are concerned for their safety because of the emotional stress that such uncertainty creates. With the current high level of media cover, the demands that remain unfilled are even larger.

Mrs. Edwina Currie, M.P.,
House of Commons,
LONDON, SW1A 0AA.

cont'd...

Mrs. Edwina Currie, M.P.

24.11.86.

We have repeatedly requested the Regional Health Authority through the District Health Authority to improve our staffing in order to provide more optimal services. Despite the fact that approximately 60% of HIV seropositive individuals in the West Midlands are haemophiliacs at our two hospitals and our requests have been strongly supported by the Regional AIDS Committee (Chaired by Professor A. Geddes), no allocations of resources have been made to date.

In recent months deaths from AIDS have occurred in the adult patients and others have progressed to having AIDS, while at The Children's Hospital a further 3 children have developed antibodies to HIV despite having been treated on heat-treated Factor VIII since December 1984. All of these events have naturally increased the anxiety of our patients and their relatives. While we will continue to try to provide the optimal care with available staff resources, we know that this will be inadequate and we may even fail to provide for some. For your interest we enclose the most recent submission to the Region, submitted some six months ago. If these requests are granted it will allow us to begin to improve our counselling services, although we fear from our observations of the evolution of AIDS in these patients, that additional resources would be required in the future.

Although the West Midlands has 10% of the country's population and a similar proportion of the country's haemophiliacs, we did not receive any of the recent D.H.S.S. allocation of funds to Haemophilia Centres because Birmingham is not a designated Reference Haemophilia Centre, although we provide services commensurate with that status.

Appreciating how busy you must be, we are grateful to you for the concern you are expressing and should you require further information, we would be happy to provide it in writing, or to meet with you in London or in your constituency for discussions.

Yours sincerely,

I. M. Franklin,
Consultant Haematologist & Co-director Haemophilia Unit,
The Queen Elizabeth Hospital

GRO-C

F. G. H. Hill,
Consultant Haematologist, Director of the Haemophilia Unit,
Birmingham Children's Hospital & Co-director Haemophilia Unit,
The Queen Elizabeth Hospital