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THE HAEMOPHILIA SOCIETY

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18th October, 1978

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LORD WILLIS OF CHISLEHURST

Dear Minister,

Following reports, some in the nature of complaints from our Groups and individual members, I am writing to ask if you will investigate the situation regarding:

- (a) the continuing shortage of Factor VIII concentrate and
- (b) the difficulties that disabled haemophiliacs are experiencing in obtaining the Mobility Allowance

In connection with the first matter we were told by Dr. David Own over two years ago that it was anticipated there would be adequate supplies of Factor VIII concentrate produced in this country by June 1977; that the United Kingdom would be self supporting so as to avoid recourse to purchasing costly commercially produced concentrates.

Whilst we appreciate that the DHSS view of what is adequate may be different from ours, and we understand that production and quality have improved, it appears that there is still insufficient to meet demands and to make the situation worse there is less money available to purchase supplies at many hospitals.

If you feel that you cannot accept this as a general statement then we will be pleased to conduct an enquiry to ascertain the full and detailed extent of the problem. We are certain, however, that such an enquiry will confirm what we hear verbally from many doctors.

The prospect of home treatment is being seriously jeopardised for many haemophiliacs and for some it is only being offered if they can produce a home freezer to store cryoprecipitate, which many doctors now regard as an outdated material for home treatment. This Society was recently asked to provide such a freezer, as well as a telephone, as a condition of home treatment for one of our members. Neither item, because of the lack of finance, could be supplied under the Chronically Sick Act and we feel that this places an unfair onus upon us.

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We would therefore appreciate it if you can tell us why the assurances given by Dr. Owen have apparently not materialised, and what are the precise plans to rectify the present unsatisfactory situation.

Regarding the Mobility Allowance, because of complaints received we have conducted an enquiry with the following results:

Out of 149 replies to a questionnaire addressed to severely affected haemophiliacs, 82 stated they had applied for the Allowance. Of these 40 had been successful (some after appeal) and 42 were unsuccessful. In the latter group 12 had appeals pending.

The remaining 67 had not applied for the following reasons:

- 34 have a DHSS car
- 10 have the Private Car Allowance
- 14 are unemployed
- 9 are at school

Our primary concern at the moment is for the 42 whose applications were unsuccessful - over 50% - a figure we consider to be far too high.

From correspondence received it is apparent to us that the primary reason for this large number of refusals to grant the Allowance is that haemophiliacs are being examined by doctors who have little or no knowledge of haemophilia. This is nothing new to us. It took over 5 years for the DHSS and its medical advisers to accept our contention that haemophiliacs have physical problems peculiar to themselves and are a special case. This was when we sought to have adapted cars instead of invalid tricycles issued to those severely disabled.

Our campaign at that time was strongly supported by the Joint Committee on Mobility for the Disabled, the Disabled Drivers' Association and the Disabled Drivers' Motor Club. The concession, when eventually made, was unfortunately withdrawn in 1976 when the Mobility Allowance was introduced.

We cannot understand why, when dealing with a relatively rare condition such as haemophilia the DHSS does not seek the advice of experienced doctors at hospitals that the DHSS itself has designated as Haemophilia Centres. Having accepted the need for such specialist Centres it appears to us to be tragic and ludicrous that the DHSS should now rely upon the opinions of doctors, such as General Practitioners, who understandably, have very little experience and knowledge of the condition. This is confirmed by some of the attached quotes from letters received. We feel that in some cases these doctors are interpreting the regulations far too rigidly and are even overruling or ignoring the opinions of acknowledged experts. This means that many of our disabled members are having what we feel are legitimate claims refused.

Even if a haemophiliac does not qualify under Paragraph a of Regulation 3 then he must surely qualify under Paragraph b which states that "the exertion required to walk would constitute a danger to his life or would be likely to lead to a serious deterioration in his health". Also, we understand that other factors which should be taken into account include pain, instability, tolerance of the exertion necessary to walk, or other adverse effects. As this has been stated in the House of Commons we would suggest that this wording should be included in the revised Regulations.

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Using public transport can, of course, be disastrous for a haemophiliac and this, plus the fact that he must have transport immediately available to get him to hospital urgently when bleeding, surely places him in a very special category. He cannot rely upon the ambulance service and in any case we feel sure you would not want a haemophiliac to call an ambulance every time he requires treatment.

It cannot be right that a haemophiliac who spends 90% of his time in a wheelchair should be refused Mobility Allowance. We would suggest that if this attitude is repeated throughout the country then it is little wonder that Mr. Alfred Morris is able to state that many millions of pounds in benefits are not being taken up by the disabled.

It was our intention to ask if the issue of cars to disabled haemophiliacs could be re-instituted but we realise that the formation of "Motability" is intended to replace the issue of vehicles. This makes receipt of the Mobility Allowance much more important and we therefore most earnestly request that you investigate the situation we have outlined. Thereafter, we hope we will receive your assurance that haemophiliacs who make application for the Allowance will be examined and dealt with by doctors, and National Insurance Officers, who have full knowledge of the condition and its effects.

There were several other items revealed by our questionnaire, for example, 16 out of 34 DHSS car recipients have major problems with repairs, mainly because of the inadequate allowance and the age of their vehicles. We trust we are correct in assuming that this is something you are looking at, at the request of other organisations for the disabled.

We would welcome an opportunity to discuss these matters and other problems with you and your officials as a follow up to the meeting we had with Dr. David Owen. At that time we all felt that such meetings might usefully be continued on a regular basis.

You will appreciate that we are under pressure from various sections of our membership to mount a campaign to rectify what they consider to be gross injustices but before taking any action we will, of course, await the favour of your reply.

Yours sincerely,

GRO-C

K.R. Polton, M.B.E.
Honorary Secretary.

Encl.