WFH Information Clearinghouse

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One of the principle aims set by the World Federation of Hemophilia for the eighties is to apply in any region of the world the considerable advances made in recent times. A good step in the right direction would be to disseminate information on the real possibilities offered by specialized treatment and care in haemophilia. A general interest for information exists not only in the area directly concerned with the treatment of coagulation factor deficiencies but also in the psychosocial and other such problems related to physical handicaps caused by haemophilia. These problem areas may be roughly divided into the following. (1) non-medical therapeutic services (such as physical therapy, occupational therapy, social guidance); (2) social and psychological concerns (family, recreation, play, sport); (3) school and work.

If one speaks with haemophiliacs or their parents, then one realizes how incredibly interested they are in all types of information to do with novel developments and new possibilities of improving their situation. The following are most often mentioned: (1) remobilization after bleeding and follow-up care; (2) other patients' experiences with this disease; (3) statutory regulations which promise them help.

The boards of management of haemophilia societies are interested above all in the following:

(1) Which objectives National Haemophilia Societies have achieved that they havenot yet achieved themselves?

(2) How were these things achieved? Most often required general information other than the supply of blood and plasma derivatives is accorded to areas such as (a) the range of payments of medical insurance agencies and the utilization of this range payments; (b) providing haemophiliacs who are unable to work with medical and social insurance; (c) the statutory regulations and assistance for handicapped persons, including tax concessions; (d) the possibility of financial assistance to pay for telephone, refrigerator, driving licence; etc.; (e) public relations.

In some countries and regions it has not been possible to obtain official approval for some of the more important requests from haemophiliacs. In cases such as these, the

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societies have had to find temporary solutions on their own initiative; in many cases, this has been done in an exemplary manner. The experience thus gained, however, cannot be utilized by others unless it can find its way beyond the region and country in which it was made. Thus, there

is a great demand for information to be transmitted to others. The first step to be made in order to satisfy this need for information is to collect and record all literature printed and distributed by local and national societies as well as publications from other sources which deal with the issues and experiences mentioned above. This published material should then be brought regularly to the knowledge of members of the World Federation of Hemophilia throughout the world. This, then, is the initial task of the Clearinghouse to be set up by the World Federation of Hemophilia: By providing the necessary information sources it will help to: (1) remedy deficiencies existing in non-medical therapeutic services, in social and psychosocial care, and in the sphere of schooling and work; (2) increase of knowledge of Haemophilia Societies which would reinforce their position when negotiating with their own authorities and governments; (3) provide suggestions for self-help without involving the authorities. We are confident that the Information Clearinghouse will deal successfully with this task. It must not be overlooked that this project will also depend upon the quality and quantity of the material received.

The WFH Clearinghouse – which will be based within the Documentation Department of the Stiftung Rehabilitation Heidelberg – does not produce information but simply stores it in a systematic order and then disseminates it. It has to rely on a regular flow of material if it is to fulfil its tasks. The principal suppliers of information must be the Haemophilia Societies themselves and all those connected with them who are engaged in the field of haemophilia, whether they produce the information themselves or whether in the course of their work they obtain such information from other sources. Everyone concerned should make a point of continually supplying the Clearinghouse with material. By endorsing this recommendation, the haemophiliac will gain the maximum benefit.

The Information Clearinghouse will operate in the following way:

- (1) It will supervise and record incoming material.
- (2) It will store it in an appropriate manner.

It will structure it in accordance with the topics specified earlier.

It will prepare a list of literature in accordance with the given structure and the available material. This material will comprise (a) all literary works published by national member organizations or societies belonging to WFH; (b) all non-medical specialized journals concerned with haemophilia and its effects, and which are available to WFH; (c) all such titles of films and audiovisual materials on the subject of haemophilia which have come to the attention of the Clearinghouse.

Correspondence shall be carried out in English.

Working languages shall be English, French, German, Italian, Spanish, Swedish.

The material shall be evaluated according to the following principles: the material which has been continually collected shall not be subjected to a selection process, since subjective judgements on the part of those

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responsible for selection are unavoidable, quite apart from the delay associated with this. Following an initial period, it is proposed to examine the material in order to see whether its contents and the structure are such that will allow the objectives set to be attained. To ascertain this, it will prove necessary to carry out a survey among information recipients and users.