Workshop III – Recommendations

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Recommendation 1

Workshop III participants agreed that one underlying theme predominated all the Workshop III presentations. That was the need for information at all levels of the Haemophilia Health Care System. Examples included the haemophiliacs 'need for information on current research results and treatment methods, the health care teams' need to know about concentrate usage, and the Haemophilia Societies' need to know about organization and legislation used by other countries. It is therefore recommended that the World Federation of Hemophilia (WFH) actively encourage, organize, support and control those mechanisms which provide for the collection, provision and implementation of information systems.

As a part of this recommendation, the workshop recognizes that it will be necessary to reflect the implementation throughout all levels of Haemophilia Societies and health care teams, and take into account the resources of the respective Haemophilia Societies. However, all areas of the world can contribute to, and benefit from, information systems.

More specifically, the recommendation should be considered to be a multi-part problem that looks at each step in the process including the collection, the provision, and the implementation. The only principle to be adhered to will be the WFH statement on information, 'all data be made freely available to all parties within the bounds of patient confidentiality'.

Recommendation 2

There are individual, regional and national differences which must be taken into account when any project of the Haemophilia Societies is attempted. It is therefore recommended that any project implemented needs to take into account the expectations of the person with haemophilia, and the differences between regions of the world.

Recommendation 3

There should be a strong role of self-care and mutual aid between persons with haemophilia, and between groups of

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patients. It is therefore recommended that a strong local emphasis should be maintained in any program of the Society. This is particularly important in the supervised self-care treatment of haemophilia where there may be a tendency for a person with haemophilia not to participate in

the activities of the health care system and in the Societies. This local emphasis must be supported by national and international programs.

Recommendation 4

There is a need to carry out functions which clearly involve more than one country. An example might be an international study of recommended concentrate doses. It is therefore recommended that for those tasks which can be identified as being international in scope, the WFH be mandated to plan, organize, manage and control any such projects. All projects should be managed by professional staff as necessary. Furthermore, all financial support received for such projects be non-designated funds so that independence of project results will be assured. All committee structures should recognize the need for representation by concerned groups.

Recommendation 5

There are many areas where a close liaison between the Haemophilia Societies and the researchers would be desirable to ensure enthusiastic participation in the study, the understanding and feedback of results, and the participation of multiple treatment centers. It is therefore recommended that the Haemophilia Societies at all levels should (1) organize to support research studies that have been identified as making a contribution to better care; (2) support studies involving multiple centers; (3) ensure that the results of the research are fed back to the haemophiliacs.

Recommendation 6

Education resources around the world are in short supply, and it is desirable to ensure optimal use of all information material.

It is therefore recommended that the Haemophilia Societies should support the WFH Clearinghouse, and by ensuring smooth flow of information between the haemophiliac and the Clearinghouse.

Recommendation 7

Education is one of the most important roles of Haemophilia Societies. It should be recognized that a 'systematic approach' (well planned and implemented) should be used, making use of local, national, and international educational materials.

It is therefore recommended that Haemophilia Societies should support education programs for all haemophiliacs, families and health care workers, making use of local, national and international resources.

It should be recognized that the education process is made up of steps including identification of education needs, evaluation of techniques and priorities, and the study of the effectiveness of implementation.

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Recommendation 8

Recommendation 10

Youths with haemophilia have special needs and concerns, and need to be encouraged to participate in their own care, in the Haemophilia Societies, and in helping others.

It is therefore recommended that groups, similar in scope to the WFH Youths, should be established at all levels of Haemophilia Societies to help meet the special needs of haemophilia youths. Youths should be encouraged to view their participation as a giving, as well as a receiving process.

The 1st International Haemophilia Conference in Bonn has been successful in encouraging participation by haemophiliacs (as needed in successful modern haemophilia therapy). It is therefore recommended that all future meetings and congresses of the WFH should have a strong role for haemophiliacs in program participation.

Recommendation 11

Recommendation 9

In most Haemophilia Societies, there is a need for financial resources to support the many activities of the Society and health care systems.

It is therefore recommended that no matter what the size of the Society, project-directed fund-raising projects should be identified. Such projects have the additional advantages of not only providing financial support, but they also provide an opportunity for Society members to work together for mutual support. Such fund-raising project ideas should be shared between all level Societies.

It is recommended that the WFH continue to support by any means possible the development of blood resources, blood fractionation and standards of blood testing throughout the world.