The World Federation of Hemophilia

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This paper will explore the importance of interrelationships and interdependence between international, national and local haemophilia organizations. It analyzes how cooperation benefits haemophiliacs and the role and rationale of internationalism.

Analysis combines four levels: the haemophiliac and his family, local groups, national haemophilia organizations or committees and the World Federation. The relationship between a local group and a national society corresponds to the connection between the national and the international – a flow of reciprocal benefits. No haemophiliac is an island into himself.

Haemophiliacs need the local organization, the local organization needs the national, the national needs the international, isolation is contraindicated in haemophilia.

Certain tasks belong to the national, others are assigned to the international. However, in various circumstances the tasks are not necessarily clearly designated. An Israeli report on voluntary services indicated that the conventional wisdom, where there is duplication between public and private should be avoided to ensure greater efficiency and the best use of limited voluntary resources, is open to question. Competitive enterprise and consumer choice in the social services market are regarded invidiously as duplication, multiplicity or fragmentation. A pervasive case can be made that redundancy of services is not always a sign of waste and/ or inefficiency, nor is it necessarily dysfunctional. It should provide a safety factor and permit more flexible response and cooperation possibilities, in addition to promoting diversity and increasing accessibility. A broad geographical participation is necessary to the decision process, especially where the effect can be multinational. If the decision is based on a narrow perspective it may do great overall damage while appearing to be entirely correct from a parochial point of view. An international overview may be necessary.

The WFH has official relations with the World Health Organization (WHO) as a nongovernmental organization (NGO). The World Federation of Public Health Associations paper on the subject of primary health states that the national and international nongovernmental organizations possess certain strengths and characteristics which enable them to function as effective and

The World Federation of Hemophilia

91

dynamic agents in the promotion of human well being. NGOs have exhibited a special capacity to work within the community in response to expressed needs. They provide important links between the community and government. They have a flexible freedom to respond in innovative and creative ways to a wide range of requests and situations. Their programmes, ranging from

research to community-based projects cover the wide spectrum of human concerns and often pioneer in the fields of health and development. NGOs include the strictly professional, specialized and technical organizations, broader based associations of persons and groups organized for a particular purpose (e.g. information and service activities, educational institutions and associations, social welfare organizations, youth groups, family planning associations, etc.). WFH assists the national member organizations and the individual haemophiliacs in the following areas: At the international level the Federation has official relations and/or liaison with WHO, Rehabilitation International, the Council of World Organizations interested in the Handicapped, International Society of Thrombosis and Haemostasis, International Society for Blood Transfusion and the League of Red Cross Societies.

The Federation's Congresses, Conferences and Workshops are of great importance in the catalytic effect these meetings have on fostering new societies and assisting the development of existing societies. Each development leads to another of greater importance and momentum. Strengthening the means of communication is fundamental. The WFH Heidelberg Clearinghouse will provide an information service. Costs to all are reduced when a central organization can provide such a service.

The WFH Administrative Handbook, recently published, can be utilized locally, regionally and internationally. The Handbook emphasizes management, i.e. how to become increasingly effective.

Future shocks to the international system and the vulnerability of national societies requires an early warning alert, a mutual vigilance relationship between the Federation and national member organizations.

One of the most interesting aspects of the Federation's efforts is the ripple effect with its impact on blood transfusion, component therapy and laboratory technology.

The WFH Bonn Conference has the task of formulating strategies for the health of haemophiliacs in the 1980s by identifying the criteria of treatment and support services required. A comprehensive system of priorities is evolving.

This paper has reviewed the purpose, the relations, affiliations, meetings, policies, programmes, of the Federation, which convey that Federation is an established and vital international organization.

Dr. Candau, past Director General of WHO said: 'The importance of WHO's work on universalism needs no emphasis, especially in a forum where we are all aware of the fact that the health safety of each individual and each country is closely bound to the production of the community of nations as a whole.'