Workshop I – Recommendations

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The members of Workshop I have drafted the following report containing seven recommendations.

Recommendation 1

Every center in every country of the world should have a haemophilia care team, which includes a core staff of a hematologist, an orthopaedist and a physiotherapist, who work closely together. The International Haemophilia Training Centers programme has been extremely useful in expanding the existence and expertise of such teams, and this valuable activity should be coordinated with the new Comprehensive Care Task Force, which we are about to create.

Recommendation 2

Every center should have a nurse, skilled in haemophilia. A Nurses Working Group should be established as a part of the Comprehensive Care Task Force, for idea exchange and for the training of nurses in any part of the world which requires assistance in this area.

Recommendation 3

A social worker is also necessary for each center. He or she should have broad-based knowledge of educational, vocational, financial, genetic counselling, and psychosocial issues, as initial goals. We should eventually work toward the provision of each of these services, either delivered by the social worker or by another health specialist, in each center. We should also study the efficacy of these efforts.

Recommendation 4

We must do everything possible to enhance the referral of haemophiliacs to haemophilia centers, in order to allow as a minimum, precise diagnosis and the development of a comprehensive care plan for each patient. A network of haemophilia care centers must be established. Neighboring regions or countries can assist each other by sharing resources and expertise. We must establish better integration of primary care doctors with this network of haemophilia centers.

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Recommendation 5

Clinical data collection should be encouraged and developed in all haemophilia centers. We must standardize our data collection systems in some cases, in order to answer specific questions via

multicenter studies. Regional standards or laboratory tests should be developed among each network of haemophilia centers. Collection and storage of plasma samples among centers will facilitate both clinical research and laboratory standardization.

Recommendation 6

Supervised self-treatment is an integral part of comprehensive care; it should be provided to all eligible patients. Formal training and follow-up is mandatory. The Home Care Committee of the WFH should integrate its efforts with the new Comprehensive Care Task Force. We must consider the use of both, concentrate and wet-frozen cryoprecipitate, as acceptable therapeutic products in self-treatment programmes. The Task Force must strongly support self-treatment as a legal and morally necessary mode of health-care delivery in those countries where it is not yet recognized as such.

Recommendation 7

In order to implement the above items, a new Comprehensive Care Task Force should be charged with the development of various strategies by which to implement comprehensive care programmes throughout the world. This Task Force should define those activities that the World Federation of Hemophilia can best participate in at the international level. The Task Force should involve itself in the quality of comprehensive care programmes, and should encourage the centers to perform measurements of patient outcomes. The Task Force should realize that developing countries must start their programmes by addressing major and basic issues such as the availability of blood resources, adequate health care finances, the presence of trained haematologists, etc., and that it will not be feasible to immediately institute complete comprehensive care programmes in many areas of the world. Nevertheless, the achievement of formal comprehensive care programmes in all areas of the world is the final goal toward which all of us should work.