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Questions by a Haemophiliac

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After the previous interesting and informative presentation there are some questions which I think might be of worldwide interest to a large number of haemophiliac patients.

My name is Wilfried Altendorf and I come from Minden. I am 39 years old, and I suffer from a severe haemophilia A.

Until 1971, I regularly spent half of the year lying in bed because of bleeding episodes. The results of those multiple bleedings cannot be concealed. To express them in figures, I should state that 10 joints are radiologically irreversibly damaged.

You will need to ask me, how it has been possible for me to move without the aid of sticks or a wheelchair? From 1971 on my daily life and my future way of life immediately changed as a result of contacting the Bonn Center, to make use of the education for home care, as this had been the only place, at that time, offering this opportunity. I must frankly confess that I had been most sceptical at the beginning as to the possible success of that new method of treatment, because I had often been deeply disappointed by new ways of treatment in the past. However, after having successfully

finished the education course for home care, I realized for the first time what it meant to live an almost normal life. I learnt to infuse when the first signs of bleeding were definitive to myself, but not necessarily to the physician because of lack of clinical symptoms of bleeding.

As a result of starting home care the periods of bed-ridden days due to bleeding episodes had been practically reduced to zero, and now I had a chance to live and particularly to work like any other healthy man.

By the early cooperation between the haematologist and orthopedic surgeon at Bonn, I had been able to prevent further changes of my joints during the following years of treatment. A physiotherapeutical treatment according to orthopedic prescription, which I execute at home and which is supported with constant factor VIII concentrate treatment, guarantees me an optimal therapy which corresponds with the clinical requirements.

Due to this method of care I have been able, for a number of years, to do my job in an almost normal way and to undertake trips around the world which are involved with

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my profession. Two or three times per year I travel outside Europe, for example to the United States, the Far East and Australia. Therefore, I am happy that in the last years I have obtained sufficient knowledge and comprehension concerning essential medical connections, so that I myself know what to do in some difficult situations. This has been most important because when studying the International Haemophilia Guide one will notice that haemophilia care facilities are still rare in some countries.

In this connection I must ask the question, if it is possible in such countries to have physicians interested in haemophiliac problems, for example orthopedics, and to educate them accordingly? In this regard, difficulties not only arise on the international level, but often also on the national level. With regard to the paper of Mr. Cornell, it seems particularly important to me that the various national haemophilia centers should develop a high degree of equal philosophy of treatment by continuous education and common discussions. This will eliminate as far as possible those difficulties of the traditional and often different methods of care for the benefit of patients. Could you imagine the advantage that we as patients would have if the majority of small haemophilia centers would conform with the recommendations of experienced centers? Another question: As daily practice proves, it often happens that the patient who has problems calls the haemophilia center in order to talk to the responsible physician. If it is possible to educate patients, it should also be possible to delegate a high degree of responsibility and decision making to nurses specially educated in the field as it has been clearly declared by Mrs. Holbrook. It should be an objective to discharge the physician from many routine decisions which could be granted to the specially educated nurse. In this regard I ask the question, how well developed are the legislative mechanisms necessary for such a situation?

Similar relief could be realized for the psychologist or psychiatrist if some of the daily psychological or social problems of a haemophiliac arising from the disease were delegated to the social worker.

It is not only in these sectors that one requires special education and delegation of responsibility. The same situation refers to laboratory examinations for hemophilia. In this connection I remember a routine physical examination which was performed by a physician a short time ago. During the examination I was informed that my diagnosis of haemophilia could not be diagnosed because the Quick value (one stage prothombin time) gave a normal result! I confess that I was very concerned with this extraordinary statement, but I also believe it still occurs all over the world.

Not only should routine coagulation examinations in the field of haemophilia be performed in special laboratories, and that means in haemophilia centers, but complicated methods of treatment too, for example, operations or the treatment of inhibitors. Therefore, I ask the question, how can a smaller laboratory outside of the haemophilia center perform routine and complex examinations in close cooperation with the special laboratory of the haemophila center? I can imagine that especially in the Third World, smaller laboratories could undertake a good deal of the routine functions with assistance by government resources. This would be particularly important due to the distance involved in many of those coun-

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tries. Bearing this in mind, I ask the question, how can the state provide adequate assistance to support a comprehensive program of treatment and care?

In this instance I refer to the practical example from the Federal Republic of Germany where legislative measures have been passed which enable me to stay for 1 week several hundred miles away from my home town and still be educated at the Bonn Haemophilia Center for self-care with the government providing the expenses for travelling and accommodation.

I am advised that in many countries, including European countries, self-care plays little or no part in haemophilia therapy. I would like to ask this question with regard to my personal example

what can haemophilia patients do by themselves to encourage worldwide self-care programs, as it gives us a high degree of personal freedom thereby improving the quality of our lives considerably, not only giving independence from the physician as many people believe?

This statement gives me an opportunity to finally thank the World Federation of Hemophilia, the organizers of this conference and particularly Mr. Frank Schnabel for giving me the chance to ask these questions which are of general interest for all haemophiliac patients. I finish with the hope that the intended task forces will be successful worldwide and that their activities will give all haemophiliacs to reach from my experience what I call a better quality of life.