Raising public awareness of arthritis/rheumatism

SP0146 CZECH SELF-HELP SOCIETY OF AS PATIENTS AND ITS ACTIVITIES

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10.1136/annrheumdis-2001.1276

The totalitarian system in former communist countries limited the activities of people and lead to their passive role in society. The individuality of people was suppressed and a paternalistic approach to patients lead to certain dehumanisation of public health care.

The velvet revolution in the Czech Republic in the year 1989 changed not only the political and economical system, but also brought new possibilities in health care. Among many other things it lead to emergence of patient self-help societies. The initiative came from both rheumatologists and enthusiastic patients. One of these societies was ankylosing spondylitis (AS) self-help society – Club of AS Sufferers, founded in the year 1990.

One of the main goals of the Club was patient education. An information newsletter has been published regularly bringing articles on all aspects of AS. Later, an audio-cassette with home exercise was released and a guidebook for patients was published and circulated among members. After an enthusiastic beginning was more and more apparent that the goals of the Club would be more difficult to achieve than expected. There is some inertia in the people's attitudes to life and it is difficult to bring new models of behaviour into reality: the responsibility of every individual for his or her life including health matters and active role in disease management. These problems are a burden for foundation of vast number of self-help groups at district level.

The prosperity of modern society is based on very effective economic system, which makes great demands on people. Some rheumatic diseases, like AS, are chronic and begin at young age. Mainly for these patients it is difficult to face all problems imposed from both the disease and life, especially employment. The negative perception of society can be difficult problem to overcome, misconceptions sometimes held by employers can bring problems in a job. The public awareness of rheumatic diseases is rather poor, the opinions, like arthritis is a disease of old age, still prevail.

To change the situation it will be necessary to inform the society about these problems. We feel that this will be one of our new goals in the future, but this goal is beyond the possibilities of an individual self-help society like Club of AS Sufferes. The solution may be in a national and, possibly, international cooperation among all organisations of rheumatologists, health professionals and patients. Only such a partnership can initiate a campaign for solving these problems. The European Manifesto or the Bone and Joint Decade 2000–2010 can be a good starting point for, probably long term, effort to improve the quality of life for people with rheumatic diseases.

The role of people with arthritis/rheumatism in campaigning and policy making

SP0150 THE EU SECRETARIAT OF THE SWEDISH DISABILITY MOVEMENT

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10.1136/annrheumdis-2001.1277

Starting January 2001, Sweden has been chairing the European Union which has entailed a lot of work but also many possibilities to influence policies, proposals, activities etc. in the EU and also in the accession candidate countries. In order to make use of the chairmanship the Swedish Rheumatism Association and some of the other DPOs (Disabled People's Organisations) in Sweden have started a project.

The project "The EU Secretariat 2001 of the Swedish Disability Movement" was started precisely in order to put focus on disability perspectives in the EU, by influencing public opinion, spreading information and increasing knowledge. The Secretariat will also arrange a European conference on the UN Standard Rules in April in Linköping in Sweden and offer accessibility advice to organisers of meetings and conferences during the Swedish presidency.

The project has been funded by the Swedish Inheritance Fund. The secretariat has been situated in Stockholm in connexion to the offices of The Swedish Co-operative Body of Organisations of Disabled People, abbreviated HSO in Swedish. The project has been led by a steering group, where among other, the Swedish Rheumatism Association, the SRA, has been represented.

Whereas the Swedish presidency in the EU focuses on the three Es Enlargement, Employment and Environment, the disability movement has chosen to interpret Environment more broadly and incorporate Accessibility into the concept.

The secretariat has published some useful booklets, for instance one called "Disability perspective in the EU – a challenge to the Swedish Presidency". in which the Swedish disability movement presents suggestions on how the EU can work to strengthen the civil rights of disabled people in the member states. By using the suggestions as a base during the Presidency Sweden can contribute to an increasing EU- responsibility for the living conditions of disabled people in Europe.

Please see www.hso.se/EU-secretariat.html/ for more information.

SP0151 LOBBY-TRAINING

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10.1136/annrheumdis-2001.1278

In August 2000, the Swedish Rheumatism Association, the SRA, started a new, exclusive training about how to influence political processes and public opinion. 55 members from our district federations take part in the training, which will continue for three terms.

The main purpose is to strengthen the districts in their work for better conditions for the members and for everyone with arthritis/rheumatism. Contacts with media are a main bulk of the