Raising public awareness of arthritis/rheumatism

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

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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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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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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

training. The need for good media strategies will be most important during the Year of Arthritis/Rheumatism in Sweden 2002, when our association co-operates with the Swedish pharmacies to focus on rheumatic diseases. In Sweden, medicine and health is the third most exposed subject in media just now.

A media analysis we have done shows that publicity about arthritis/rheumatism and the SRA generated about 60 millions possible occasions for media-consumers to pay attention to these subjects during the first six months in 2000. The analysis is based on 365 newspaper articles and broadcasting reports. Most of these (75 percent) were common information about people with rheumatic diseases and different applications of treatments. The SRA was exposed in 25 percent of the articles and reports.

When media pays attention to rheumatic diseases, the most frequent subject is pharmaceutical drugs followed by personal interviews with people suffering from arthritis/rheumatism and facts about the diseases. Even when the Rheumatism Association is exposed, the main subject is pharmaceutical drugs.

People with arthritis/rheumatism are the main figures, followed by doctors and scientists/experts. When attention is paid to the association, local representatives and members are important figures.

The analysis shows that there is good ground and many possibilities for the SRA to increase the media attention, take a larger part of the total publicity and focus on a strong and clear image.

Main items in the lobby-training is:

- Civics
- Rhetoric and argumentation,
- How to influence political processes
- Contacts with media

The training is partly IT-based and includes four meetings on a national level (each for two days), mixed with regional meetings and homework. Between the meetings, Intranet connects participants and coaches, where they chat, ask questions, discuss and learn from each other. Memos, working papers, subjects for homework, etc are available on Intranet.

Best practice in relationship between patient organisations and the pharmaceutical industry

SP0163 PATIENT PARTNER PROGRAM

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Ms. Zasterova describes her participation in the Patient Partner program sponsored by the Searle Company. The aim of the program is to train people suffering from rheumatic arthritis and osteoarthritis so that they could become teachers/advisors to other patients with rheumatic disease and so start continuing rounds of patient-to-patient teaching. The training consists of:

- Regular meetings
- Lectures on medicaments, psychology, rehabilitation, etc.
- Practical presentation of medical aids
- Teaching materials
- Final test of knowledge gained

The program not only provides information that helps them understand and influence their own disease, but also engages

patients in sharing the knowledge and encourages patients to mutual help.

SP0164 REUMAÅRET 2002, A NATIONAL THEMATIC YEAR ABOUT ARTHRITIS/RHEUMATISM

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Background In 2002 Apoteket AB the National Corporation of Swedish Pharmacies will carry out a thematic year about Arthritis/Rheumatism in co-operation with Reumatikerförbundet the Swedish Rheumatism Association, the SRA. There are 884 pharmacies in Sweden and our 24 regional and 201 local associations have several pharmacies to co-operate with.

The King of Sweden is patron of the thematic year and will inaugurate it in January 2002.

Objectives The qualitative objectives of the thematic year are:

That the SRA is perceived as an active disability association with a broad variety of activities for all age groups. That the SRA take good care of our members, especially considering the newly recruited members. Improved medicine usage

We have several quantitative objectives, for instance:

Rheumatic diseases and their consequences are well-known. Suggested measures from the SRA in order to improve the situation of people with rheumatic diseases is well-known in society. To recruit new members and reach a membership of 60000 members.

More active members in the age group of 50 years or less. At least 1000 activities together with Apoteket AB during the thematic year.

Methods During 2001 we will prepare the thematic year within the SRA by making all the necessary preparations through education, seminars and conferences. We want our 24 regional and 201 local associations to be involved and prepared in all the activities together with the Pharmacies. Externally we prepare for the thematic year through a national conference together with the Pharmacies. This conference will be followed by regional and local conferences all over Sweden. The activities during the year 2002 will mainly focus on the local perspective, the majority of the activities will take place in co-operation between the local pharmacy and the SRA local associations. We will produce a catalogue of activity proposals and deliver it throughout the SRA and create a contributory bank with names and the subject area of lecturers, specialists and experts to employ for meetings, seminars etc.

Some examples of activities are:

Seminars about different rheumatic diagnoses. Members inform about their local association at a pharmacy. Local actions about the lack of proper treatment and rehabilitation possibilities for people with rheumatic diseases. A research-site on our website.

Results The results are connected to our objectives and we will try measure whether we have reached them through surveys before and after the thematic year. This will be the basic data for decision-making when we evaluate the thematic year and try to implement good practices and activities in the SRA. The recruitment objective is easily monitored every month through our membership register. One long-term result will hopefully be continuing local co-operation between pharmacies and local