Some data characterising the development and activity of CLAR were followed up during last ten years. Thus an increasing number of members of CLAR were noted. This number doubled during the last year, i.e. to 203 persons. The number of issues of the CLAR Bulletin edited every three months increased in the same extent. The interest of patients to participate in rehabilitation and in yoga meditation expanded too/to about 40 patients every week/.

These encouraging facts should be considered as consequence of CLAR activities mentioned above and of enhanced public awareness of rheumatic conditions too.

The majority of CLAR actions are organised with the help of the Institute of Rheumatology in Prague and with the support of pharmaceutical industry.

Improving the health professional/patient relationship

SP0174 PATIENTS' INFLUENCE ON HEALTH CARE, AND SOCIAL CARE

DD Magnusson. *The Swedish Rheumatism Association, Region Jamtland, Offerdal, Sweden*

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A short presentation of how a Rheumatism NGO can work on a local level together with the County Council, the Health Care Employment Service Agency and the Social Insurance Office. Together with the health professionals we have produced education material, which is possible to use for health professionals, patients, the Employment Service Agency, the Social Insurance Office and the County Council. This material is called "For whom (it may concern)". The book has 12 chapters which contains these subjects: Humanity, quality of life, for whom, whose goals, meeting people, to take responsibility – right to self-determination, to make demands, who has the authority, rehabilitation economy, following up and evaluation, conventions, laws and regulations. The material contains four parts in each chapter, the first part is sayings, the second part is a factual part, the third part is a case example, the fourth part is a number of questions which are solutions orientated. Everyone can use this material, alone or in groups.

We are functioning, as patient experts on matters like, rehabilitation, education and how to approach the patient. My experience is from a region in the middle of Sweden called Jamtland. Jamtland has a big area on 49 500 km² with a population of 129 000 people, which means 2,6 persons per square kilometre.

Patient priorities in medical and social research

HP0038 PREFERENCES FOR IMPROVEMENT IN HEALTH: A COMPARISON BETWEEN AGE, SEX AND EDUCATION-MATCHED PATIENTS WITH OSTEOARTHRITIS (OA) AND RHEUMATOID ARTHRITIS (RA)

¹T Heiberg, ²B Slatkowsky-Christensen, ²TK Kvien. ¹Nursing Director's Department, Ullevål University Hospital, Oslo, Norway; ²Department of Rheumatology, Diakonhjemmet Hospital, Oslo, Norway

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Background Awareness of patients' preferences are of salient importance for health professionals in today's health care system. Preferences both on an individual and on a group level form the premises for the provision of an effective and efficient health care service.

Objective The aim of this study was to examine in which areas of health a group of patients with OA would most like to see improvement, and to compare their preferences with the preferences reported by matched RA patients.

Materials and methods Fifty-one patients (mean (SD) age 66 (4) years, 4 (8%) males, mean (SD) years of education 12 (3)) with generalised OA including hand OA, previously referred to a rheumatology outpatient department, underwent a comprehensive clinical examination including completion of several self-reported health status questionnaires. Among these were AIMS2, MHAQ, SF36 and joint pain VAS and fatigue VAS. These OA patients were compared with 51 RA patients matched for age, gender and level of education who were recruited from the Oslo RA register and had previously responded to identical questionnaires. All patients were asked to check three out of twelve health areas in which they would most like to see improvement (AIMS2, question 60). Scores of health status were computed from the different scales of health status questionnaires. Comparisons between the two matched patients groups were performed by McNemar tests (categorical variables) and paired analyses (continuous variables).

Results Out of the OA patients 82.4% reported priority for improvement in pain, compared to 58.8% of the RA patients ($p = 0.02$, McNemar test). Other health areas had lower priorities in both groups without any significant group difference and were distributed as follows among the OA/RA patients: Mobility level 5.9/17.6%, walking and bending 31.4/25.5%, hand and finger function 45.1/52.9%, arm function 9.8/23.5%, self-care 11.8/21.6%, household tasks 39.2/31.4%, social activity 2.0/11.8%, support from family 3.9/3.9%, work level 3.9/5.9%, tension 11.8/7.8%, mood 25.5/17.6%. Across different instruments OA patients also reported numerically more severe pain and mental health scores than RA patients whereas RA patients had significantly worse scores within the dimension of physical disability.

Conclusion Although being a preliminary study with only 51 patients in each group, these findings indicate that pain is the area where both OA and RA patients would most like to see improvement, and that patients with OA have pain as an even higher preference for improvement than patients with RA. Consequently, pain is the area of health that deserves increased attention in clinical practice, both for patients with OA and RA.

Raising public awareness of arthritis/rheumatism

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

MO Konrad. *International Contacts, Club of as Sufferes, Prague 2, Czech Republic*

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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

BJ Allardt Ljunggren. *Political Division, The Swedish Rheumatism Association, Stockholm, Sweden*

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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

L Tillström. *The Swedish Rheumatism Association (SRA), Stockholm, Sweden*

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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