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Good care means development and keeping up with current advances. As new research information about rheumatic conditions is emerging and their care forms are developing, the focus of the work of people involved in care and the content of their jobs are also changing. The most recent information about e.g. the potential threat posed by rheumatoid arthritis on small joints, already in early stages of the disease, increases the significance of early intervention by occupational therapists and podiatrists. On the other hand, the spreading of various combination therapies and biological drug therapies has shifted the focus of nurses' work from care to counselling.

Various social phenomena also affect the work challenges of people working in the field of musculoskeletal disorders. In a great part of Europe life expectancy has been increasing. Population grows older and musculoskeletal symptoms increase. Moreover, an increasing number of Europeans gets less exercise than is recommendable to ensure musculoskeletal health, and consumes more calories from food than the body can burn. The significance of preventive work is constantly increasing. Instead of reacting there should be an increasing range of proactive measures to minimise future health problems.

Evidence-based knowledge
Practically everyone is exposed to health information from media campaigns. The same basic statements about health maintenance apply to the prevention of cardiovascular diseases, musculoskeletal disorders and diabetes alike. But what do we need to supplement this information, to actualise it as a desire and skill to attend to one's own musculoskeletal health? Health professionals become coaches helping to learn skills that promote lifestyle changes. In that task a professional needs more in-depth knowledge about various dimensions of motivation, as it depends on each individual as to which type of motivation leads to a desired outcome. In addition to motivation, also confidence in the capacity to achieve the set goals is needed. Personality has a bearing, too: Some people are very susceptible to feedback, but with others instructions of professionals merely lead to strengthened resistance. In a counselling situation the same information content should be adapted on the basis of recipients' varying worlds of ideas and experiences.

Many kinds of information are available. People are increasingly turning to Dr. Google as their first choice after experiencing various musculoskeletal symptoms. At worst, when arriving to the doctor's office they have a fixed opinion, not only about the diagnosis, but also about the necessary tests and medication. There are good sites, managed by academic bodies and patients' organisations, providing dispassionate, evidence-based information on various musculoskeletal symptoms and disorders and their treatment. Websites are, however, no substitute for medical examination or care. There are also a great number of sites providing contorted information based on uncorroborated beliefs. Where could a layman learn to be critical when navigating in the vast and variegated multitude of health information sites? This, too, presents a challenge.

Requirements are increasing for health professionals with regards to keeping up with time, applying scientific knowledge to practical work with patients, and continuous development and assessment of own work. In addition there is a need for dialogue and cooperation enabling an adaptation and synthesis between knowledge from different disciplines and studied interventions.

Co-operation is a key element also in a broader sense. This means co-operation, not only with different specialists' or their teams, but also co-operation across national borders and organisations. Also the political aspects of the European health care system have to be
taken into consideration, not to mention the health projects beyond European borders. At the moment the EULAR AHP Committee has connections with the American colleagues of the ARHP. EULAR is working on various levels together with the UN, WHO, ILAR and with other international institutions and campaigns.

A Decade for bones and joints
More than 400 million people suffer from musculoskeletal problems. Musculoskeletal injuries from traffic accidents and wars are shocking, but the risk factors of slowly developing and possibly disabling musculoskeletal disorders are not taken seriously enough. Musculoskeletal disorders are not taken into consideration in national decision-making in the same way as more dramatic diseases are, even if the effects of musculoskeletal disorders on national health and economy were bigger.

Bone and Joint Decade (BJD) 2000–2010 is a worldwide project aiming at slowing down the progressing of musculoskeletal conditions and injuries, promoting their care and rehabilitation and making their social burden visible. It is a project covering almost 100 countries which, in addition to the endeavours of the global network, has national, regional and local initiatives. The project is also a good example of how, in order to achieve wide-ranging goals, common endeavours by all parties are needed – by people suffering from the disorders, professionals, researchers, and decision-makers. It is wide-ranging, multidisciplinary co-operation at its best.

The project is implemented in a variety of ways in different countries. Great variation has occurred e.g. in the way in which different associations of specialist physicians, other health professionals and patients' organisations have participated in the national implementation. Also the focus has varied. In many developing countries, for example, special attention has been paid to prevention of traffic accidents. In many European countries, however, attention has been paid especially to prevention of osteoporosis and promotion of back disease care.

This is the ninth year of the campaign, after which two years are remaining. Only after the conclusion of the project will it be possible to assess its meaning in the promotion of musculoskeletal health. It is already clear that the goals will remain relevant even after the conclusion of the project, and their promotion will require all of us to act side by side. Are you already involved in your own national initiative?

Jaana Hirvonen
Editor

According to Professor Liana Euller-Ziegler, the President of EULAR 2008 Local Organising Committee and the BJD Coordinator in France, the benefits of multidisciplinary operation have been notified and experienced to be important in the French health care system.
– I am running, on behalf of the French Society for Rheumatology, a survey of the current experiences on therapeutic patient education in France, including notably multidisciplinary teamwork interventions, Euller-Ziegler says.

In this Issue
This Newsletter is a special edition distributed in EULAR’s Congress in Paris. We introduce a wide range of subjects with health professionals as the common link. The articles, columns and news items discuss life and work with rheumatic diseases and MSDs. We take a look at recent AHP dissertations, educational visit reports and of course the Congress in Paris. We also shed some light on the efforts done in the EU front and how the importance of multidisciplinary care is seen in the United States. Please enjoy the Newsletter and give us tips for the future issues!
The first AHP Teach-the-Teacher Course

ULA R considers education as one of its most essential tasks. Up till now, the educational activities for Allied Health Professionals have consisted of the annual congress, travel bursaries, and educational visits. However, there is a much broader variety of knowledge and skills among the different professions and countries in Europe, resulting in different standards of care. The traditional EULAR educational activities do not properly meet the learning needs of the European Allied Health Profession in Rheumatology (EAPR). Besides, we discovered a clear need for a post qualification course programme on the diagnosis and treatment of rheumatoid arthritis (RA) and osteoarthritis (OA) for AHPR, developed and dispersed by AHPs. This is why we decided to launch the first EULAR AHP Teach-the-Teacher Course focusing on the recent state of the art where diagnosis and treatment of RA and OA patients are at stake but also on ways to spread this knowledge through various educational activities in your own country. Good instructors are crucial for the dissemination of the knowledge we have generated within EULAR. This is why we also included a Teach the Teacher perspective in the course programme.

The future courses are aimed at health professionals from fifteen European countries; namely, one nurse, one physiotherapist and one occupational therapist from each country. Most participants will have some experience in teaching. However, many will not necessarily have much experience in teaching several interactive courses, using different teaching methods depending on the learning goals towards which one might aim. When thinking about learning and education, it is important not to think about giving lectures only, but also, for instance, about skills and scenario teaching or using group discussions. Some of the methods we will work with may be new; others might be more familiar to the participants.

As it is almost impossible to acquire valid information about the knowledge and skills of the different AHPR in European countries, the AHP Education Committee will also assess the learning needs of the participants attending the course. With the information obtained from this course, the AHP Education Committee will then be able to launch a multidisciplinary introductory course in rheumatology for Allied Health Professionals in Europe. The first course took place at Leiden University from 15th to 18th of May 2008. The course leaders were Peter Oesch and John Verhoef. We are happy to note that the feedback from this pilot course was rewarding and will influence the structure of the future courses.

A detailed course report will be given at the EULAR Congress during the "Meet Standing Committee" meeting held on Friday, the 13th of June, between 10:15 and 11:45. The results of the learning needs of AHP in Rheumatology will also be presented.

John Verhoef
Chairman of EULAR Standing AHP Committee
Under the leadership of the EULAR President, Professor Ferdinand C. Breedveld, EULAR has defined its objectives and goals for the next five years. The eight overall objectives for EULAR to be achieved by 2012 were presented in the EULAR AHP Newsletter 2/2007. Altogether thirteen subgroups were established and were asked to consider what the overall EULAR objectives 2012 mean in their own context of interest. Each of these subgroups developed their own goals within the EULAR strategy 2012. The draft of the five AHP goals (please see also EULAR AHP Newsletter 1/2007) were reviewed at the EULAR strategy workshop held in September 2007 in Zürich and are now finalized.

The goals are:

1. By 2012, the AHP in EULAR will be recognised as a professional and effective organisation, worth belonging to and working with. At least three working groups will be developing, for instance, educational courses, publications, policies, recommendations for care, scientific reviews of abstracts and grants identifying them.

2. By 2012, the AHP in EULAR will have established effective partnerships by running at least one project both with international health professionals’ organisations in rheumatology (non-European associations such as ARHP) as well as with international health organisations (such as WHO).

3. By 2012, EULAR will compile a core curriculum of training and continuous education for Health Professionals in Rheumatology, with a focus on nurses, physical and occupational therapists. This core curriculum can be translated and transported to all member countries that wish to use it. ARHP/AHP should consider cooperation on education.

4. By 2012, the AHP in EULAR will have encouraged local initiatives for establishing the foundation of five new national AHP organisations in rheumatology and thus enabling them to become official members in EULAR.

5. By 2012, the AHP in EULAR will have established evidence-based recommendations for the non-pharmacological treatment of patients with the most common rheumatic diseases, e.g., osteoarthritis and rheumatoid arthritis. Encourage scientists to perform research in this field in order to provide this evidence.

The AHPs have already initiated some projects (see EULAR AHP Newsletter 2/2007) contributing to achieve the defined goals. However, further AHP projects and measures are needed to successfully collaborate within the EULAR strategy 2012. The EULAR Executive Committee will meet in June 2008 to approve the first set of specific projects and measures that will contribute to further “mobilizing our planet” as emphasized in the objectives. We would very much hope like to see further AHP projects on the priority list.

Peter Oesch
EULAR AHP
Vice-President

The AHP banderol depicts some of the aspects of health professional work. The focus is on people with rheumatic disease.

The programme at the booth

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PS Please also make sure to be there at lunch time! Attending such a congress requires a lot of energy that has to be regained at certain times. We will provide beverages and sandwiches! In other words, please make use of this new facility.
Interviewing Congress Manager Ernst Isler

When Congress Manager Ernst Isler joined EULAR in 2002, he had 27 years of experience in administration, process management and project management with IBM, nationally and internationally. However, “congress business” was completely new to him at that time. EULAR 2008 in Paris is now the sixth congress Ernst Isler has been responsible for.

When do you make the first actual plans for a new congress?

– Preparing for any congress involves several phases. Obviously, the first phase is the selection of the city and venue. This is ideally done five to six years in advance and involves reservation of the congress centre and booking approximately 10,000 hotel rooms throughout the city. We do this in cooperation with our Congress Agency MCI with which we have been working for more than seven years now.

The second phase begins some two years before the event and involves planning the social activities that will take place in the host city and making the appropriate reservations. In this phase, we also make a detailed plan of how we want to utilise the congress centre for the various elements of the congress: scientific sessions, exhibition, posters, and the welcome reception. Also the preliminary call for abstracts is prepared.

The third phase is all about the detail and starts exactly one year before the congress. The setup of the “congress content” is a full 12-month-long activity, and includes everything from the scientific programme – in close cooperation with the EULAR Scientific Committee – through to the acquisition of exhibition partners, abstract submission, scoring and selection, invitation of speakers, registration of delegates, organising press conferences, and extends to everything that delegates see, feel and experience during the event, literally everything! None of this would be possible without the professional support from our Congress Agency and various other partners.

Which congress so far has been your best professional experience?

– Every congress is a different experience. In each congress, some things work extremely well and others do not work quite so well. The most important thing is that the delegates – wherever possible, experience a smooth-running event, regardless of any “backstage” complications. In this respect, it’s impossible to name the best congress so far – it would
somehow be unfair! Of course, I do have my personal list of favourites…

Are there special features you have to consider while organizing the Paris Congress?
– The unique architecture of the Paris Congress Centre imposes some special challenges on our congress organisation. One of the items we need to keep a close eye on is the circulation of the delegates in the building since the congress centre is spread across four floors, and there are some bottlenecks to overcome.

What is the most rewarding thing in the process of organizing a congress?
– There are two aspects to this: an “internal” one and an “external” one. The internal one is the extremely professional and cooperative collaboration with the various bodies involved: the EULAR Committees, the Congress Agency, the Press Agency, the corporate sponsors, the speakers, to name just a few.

The external one is satisfied and smiling delegates who might say: “I have been to many congresses in my life, but EULAR is the one I won’t miss next year.

Apparently EULAR congresses cannot get any larger in the future. How do you see the future setting of a EULAR Congress in 10 years time?
– I’m not sure I completely agree with this statement! There are some medical congresses twice the size of EULAR, so we still have room to grow. But size is not what really matters – it is quality that makes the difference, in terms of scientific content and delegate satisfaction.

Over the next years, we would love – and expect – to see EULAR continue to grow and be seen as the rheumatology scientific event not to be missed.

Is there a happy incident you could share with us conserving the earlier congresses?
– Every happy delegate crossing my path at the congress is a happy incident. And it is particularly rewarding to see, during the four days of the congress, how everything that was prepared by dozens of brains and hands and executed by almost 200 staff members is turned into a great living event. But there is one special occasion that comes to mind: at my first congress, in 2003, in Lisbon, when we arrived on the Saturday before the congress started, an army of workers was still in four of the session rooms, finishing the seats, stages and the audiovisuals... which is really cutting it fine! So I can tell you, there was adrenaline flowing that day and a lot of work went into making sure everything was in place for when the curtains opened the following Wednesday which, I’m delighted to say, went very well indeed!

What do you think about the environmental challenge that a congress poses?
– The environment is such a hot topic at the moment, and the EULAR Executive Committee has come up with a set of recommendations with respect to the Annual EULAR Congress. Obviously, some environmentally contentious issues such as travelling to the congress are unavoidable when organising an event for 12,500 participants, so EULAR is focussing its attention on increasing the opportunities for individuals to be environmentally sound.

By the way, did you realize that all waste and trash in the Barcelona Congress was duly separated in accordance with environmental aspects? We believe that it is more important to do something than being highly visible.

Is there something else you would like to point out to our readers?
– We actively invite every EULAR attendee to give us feedback about their experience of the EULAR Congress. We want to know what we could improve, not only on a global level, but also for the individual delegate. Some items may be easy to achieve, some more difficult, but hopefully none impossible.
Providing collaborative multidisciplinary health care services within the U.S. health care system: challenges and opportunities

Karen L. Kerr is a board-certified pediatric nurse practitioner in the Division of Immunology, Allergy and Rheumatology at Children’s Hospital of Michigan in Detroit, where she has been practicing pediatric rheumatology since 1993. Ms. Kerr is also an adjunct faculty in the graduate nursing program at Wayne State University College of Nursing. Ms. Kerr is the Immediate Past President of the Association of Rheumatology Health Professionals, a division of the American College of Rheumatology. You can contact Ms. Kerr at kkerr@dmc.org.

Arthritis and other rheumatic diseases are among the most common chronic diseases and a major cause of disability worldwide. Rheumatic diseases affect persons of all ages, genders, races, and socioeconomic status and can have a profound impact on the affected individuals’ quality of life, shaping their physical, psychological, and social well-being. In the past decade, significant advancements have been made in the diagnosis and management of arthritis and other rheumatic diseases. There is increasing evidence that early diagnosis and treatment of rheumatic diseases can significantly improve patient outcomes and quality of life.

Interprofessional collaboration
Meeting the needs of persons with complex, chronic rheumatic diseases is best achieved through provision of collaborative, coordinated multidisciplinary care. According to the American College of Rheumatology’s practice guidelines for the management of rheumatoid arthritis, “optimal longitudinal treatment requires comprehensive coordinated care and the expertise of a number of health care providers.” Effective interprofessional collaboration involves members of different disciplines working together as a coordinated team, utilizing the expertise of all members, to achieve a common goal. The combined skills and expertise of the multidisciplinary team are integrated to provide a level of care that surpasses what individual members can provide independently. Purported benefits of coordinated interprofessional care include increased patient satisfaction, increased patient compliance, increased care efficiency, decreased health care costs, and reduced hospitalizations.

The provision of collaborative, coordinated multidisciplinary care to persons with complex, chronic illness can be challenging in today’s health care environment where the demand for comprehensive, quality health care services is coping with dwindling resources and fragmented health care delivery systems. Traditionally, the members of rheumatology multidisciplinary teams were located within the same health care facility. Team members met in face-to-face patient care conferences on a regular basis to ensure communication and coordination among team members. However, increasing health care costs, geographic health provider shortages and restrictions imposed by health care insurers are changing the boundaries and structure of multidisciplinary teams.

Health care insurance system
Health care expenses in the United States are skyrocketing. In 2005, health care expenses accounted for approximately 16 percent of the U.S. gross domestic product; a greater percentage than any other industrialized country in the world. Unlike most major industrialized nations, the United States does not provide universal health care insurance for its citizens.
Most Americans have private health insurance sponsored through their employers. Government sponsored health care is primarily restricted to the poor, elderly, and disabled. Increasing health insurance premiums are making health insurance unaffordable for both individuals and employers in the U.S. As a result, many employers have reduced or eliminated health care benefits, leaving increasing numbers of Americans uninsured or with inadequate health care coverage. According to data from the U.S. Census Bureau, the number of uninsured Americans reached 47 million in 2006, which included 8.7 million children.6-7

In an effort to contain costs, many U.S. health insurers have limited access to health care services and providers within defined networks, allowing patients to go out of the network for services only when there is no in-network provider. In addition, health provider shortages in many geographic areas can impede access to multidisciplinary health care services, especially in rural areas. Thus, patients may be required to travel to different health care facilities to access the services of different health providers, resulting in multidisciplinary health care services being provided across organizational settings.

**Integration of technology**

In order to provide coordinated multidisciplinary health care services across organizational and practice settings, health professionals must redefine the boundaries of the multidisciplinary team and establish new methods to ensure effective interprofessional communication and collaboration across varied health care settings. This will require integration of new technologies and communication tools, such as electronic medical records, digital imaging, and teleconferencing into clinical practice. Ongoing interprofessional research is needed to evaluate the effectiveness of these and other technologies in facilitating interprofessional collaboration and communication and the provision effective coordinated multidisciplinary care to improve health outcomes for persons affected by arthritis and other rheumatic diseases.

Karen L. Kerr  
MSN, NP, CPNP, PNP-BC

The national representation in the EULAR Standing Committee of Allied Health Professionals in Rheumatology

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Presently, fifteen European countries have a representative in the AHP Standing Committee. At the moment, the Committee has four national organisations as members: the British Health Professionals in Rheumatology (BHPR), the health professionals in rheumatology Switzerland (hpr), the Netherlands Health Professionals in Rheumatology (NHPR), and the Swedish Rheumatology Forum (SveReFo).

**New members are welcome to join.**

**References:**
7. Center on Budget and Policy Priorities. More Americans, including more children, now lack health insurance; August 2007. Available at http://www.cbpp.org/8-28-07health.htm
Musculoskeletal disorders (MSDs) bring pain and distress to millions of workers in the European Union every year. European Commissioner for Employment, Social Affairs and Equal Opportunities Vladimir Špidla assured that he – and the Commission – is committed to tackle the problem of musculoskeletal disorders in the workplace. Špidla held an opening speech at the Closing Event of the Lighten the Load campaign in Bilbao on the 26th February 2008. The Lighten the Load campaign was organized by the European Agency for Safety and Health at Work and it involved all EU member states and EFTA countries in the campaigning activities last year. The overall aim of the European campaign on MSDs was to support employers, workers, safety representatives, practitioners, preventive services, policy makers, and other stakeholders in improving MSD prevention at workplace level. A special focus was on multidisciplinary approaches with particular emphasis on the role of social and organisational support in enabling workers both to return to work and subsequently to sustain employment when experiencing MSDs.

– Musculoskeletal disorders are, indeed, the most common work-related health problem in Europe. In my own country, the Czech Republic, MSDs account for one-third of all occupational diseases. Tackling MSDs is therefore a priority for the EU if we are to create more and better jobs in Europe. It is essential if European workers are to enjoy not only better quality jobs but a better quality of life and a higher standard of living, Špidla said.

MSDs also impose a heavy financial penalty on workers. In the most chronic cases, the treatment of and recovery from MSDs are often unsatisfactory – the result could be permanent disability and loss of employment for the worker.

– MSDs exact a toll on businesses and governments. In some Member States, 40 percent of the costs of workers’ compensation are due to MSDs and up to 1.6 percent of gross domestic product (GDP) is lost because of them. So tackling MSDs is not only a safety and health issue but also an economic necessity, Špidla reminded.

Action has been taken

The dangers of MSDs are recognized throughout the European Union. The Lisbon strategy objectives include creation of more and better jobs in Europe. According to Špidla, tackling MSDs would contribute to the achievement of this objective. The Community strategy 2002–2006 on occupational safety and health at work already identified MSDs as a priority area for preventing occupational illnesses.

– And Social Partners in their position papers on the new Community occupational safety and health strategy running from 2007 to 2012 have again stated that MSDs should be a priority. Legislation, such as the Framework, Manual Handling, and Display Screen Equipment (DSE) Directives, are already in place and helping to address the problem of MSDS. And right now, new initiatives are under development at EU level in the area of prevention of work-related musculo-skeletal disorders, Špidla told.

Based on the results of the second phase consultation of the European social partners, different regulatory and non-regulatory options are currently under discussion in the framework of the preparatory work for an extended social and economic impact assessment, which in Špidla’s opinion will support and form part of any future Commission initiative in this area.

Prevention is the best method

Several Member States have identified a number of ergonomic risk factors, such as manual handling and repetitive work, which is why occupational safety is health priority.

– When I launched the Lighten the Load campaign in Brussels last June, I said that we needed a holistic approach to MSDs that integrates both primary prevention and the return to work of those who suffer MSDS. We need to help those at work to stay at work, and help those without work back into work. Company management is in a key position. Management systems need to better tackle factors that in the long term cause such disorders and diseases. Disability and early retirements are not our solutions. These words remain true almost a year later, Špidla said.

He noted that prevention is the best method to tackle MSDs but for workers who are already suffering from MSDS, the challenge is to help them remain at work and, if necessary, reintegrate them into the workplace.

– Employers need to find ways of rehabilitating those who have suffered MSDs and help them to return to work – quickly. The evidence shows that timely and appropriate reintegration strategies increase the likelihood of return to work after illness or an accident. For back pain for example, it is important for workers to stay active and return to ordinary activities as early as possible. And, combining actions – such as providing clinical management, rehabilitation programmes and early workplace intervention – is more effective than taking any action on its own. We need to listen carefully to what experts say and put it into practice if we are to tackle MSDs effectively, Špidla said.

Source: Špidla’s speech at the Closing Event of the Lighten the Load campaign on the 26th February 2008
EULAR goes EU

This year, EULAR celebrated the 5th anniversary of the Alliance Against Arthritis (AAA). The alliance is EULAR’s activity and lobbying arm in Brussels. The five AAA events hitherto have been an intensive collaborative effort of EULAR’s people with arthritis, Health Professionals, and EULAR’s rheumatologists – efforts which have shown that EULAR has grown into a single “family” of its constituencies and how much can be jointly achieved.

When we set out five years ago, rheumatology was not on the radar screen of the EU bodies at all and the name EULAR was totally unknown in Brussels. Needless to say, research programmes did not contain calls for rheumatic diseases and disability legislation, when implemented at all, would not see disability due to rheumatic diseases as an important area. This has dramatically changed over the short time since AAA started.

A first major step was the Written Declaration on Rheumatic Diseases which was signed by a vast majority of the members of the European Parliament in the summer and early fall of 2005. Aside of the fact that only a small fraction of proposed written declarations attain majority support by the European Parliament, this declaration focussed on research, health access, and disability issues.

To our dismay, the Research Commissioner did not accept rheumatic diseases as an explicit “major diseases” area for funding, but rather grouped them together with “other chronic diseases”. What are the consequences? Bizarrely enough, the plan for the third call of the 7th Research Framework Programme (FP7) does not even contain a single rheumatology topic! This has been an issue of intensive discussion at AAA in 2008.

A fresh start for lobbying

Indeed, at this year’s AAA meeting, a representative of the Commissioner for Employment, Social Affairs and Equal Opportunities Vladimir Špidla expressed his astonishment that rheumatic diseases had not been awarded a major disease status in the research area. Therefore, there is more to fight for and we all should struggle so that in each of the subsequent calls of the FP7, there must be several topics on rheumatic diseases. Moreover, upon mid-term review in 2010 and even more so in FP8, rheumatic diseases must become “major diseases”.

On the other hand, the Health Commissioner Markos Kyprianou has recognized rheumatic diseases as a major health problem and thus given it a “major disease” status. Thus, as regards health and equal opportunity issues, EULAR is currently in well-reaching negotiations with the respective Cabinets of the Commissioners and the Directorates General of the respective areas, and we hope that the new Declaration, launched by EULAR in Brussels in early March 2008, will be awarded recognition through directives and legislation in the near future.

Importantly, at this year’s AAA meeting, EULAR also launched its new office. With the help of Sören Haar and his team from the European Affairs Consulting Group (EACON), our lobbyists in Brussels, we will have more direct contact with the EU bodies.

EULAR certainly goes EU – we have learned a lot over these few years, and we have achieved a lot although not as much as we set out to attain. We need to strengthen our forces, increase the activities in Brussels at all levels, the Parliament, the Council, the Commission, and the individual Directorates. Rheumatic diseases affect a majority of the adult population of Europe at one point or another, and often chronically; they need to be distinctly noticed on the EU screen. Let’s do it together!

Josef Smolen
Professor of Medicine, Medical University of Vienna, Austria

The new Declaration given in 2008 called for the following:

1) Declare that there is an urgent need for recognition of the needs of people with rheumatic diseases in order to abolish the misperceptions that rheumatic diseases affect only older people or have little consequences to the individual and society.
2) Declare that people with disabilities related to rheumatic diseases should enjoy the same rights as any citizens of the European Union and have the same individual choices to ensure full inclusion in society.
3) Declare that people with disabilities related to rheumatic diseases should be provided with the appropriate conditions for self-development and independent living to make use of their potential as citizens.
4) Declare that people with disabilities related to rheumatic diseases should have the right to work, with the necessary adaptations and improvements to accessibility made to accommodate our needs.
5) Declare that people with disabilities related to rheumatic diseases should have the right to obtain goods and receive services accessible and independent living.
6) Declare that people with disabilities related to rheumatic diseases should in order to have the right to receive the best possible treatment and rehabilitation services.
7) Declare that people with disabilities related to rheumatic diseases should have the right to claim a rheumatic condition as the reason of unemployment or long-term sick leave.
8) Declare that persons with reduced mobility should be ensured accessible transport systems and, where necessary, assistance in employment in up to 50% of cases.
9) Declare that persons with reduced mobility should be provided with a fully accessible public environment.

The Written Declaration on Rheumatic Diseases from 2005
Preventing work disability with patients with rheumatoid arthritis

Several research studies regarding prevention of work disability have been conducted in the Inflammatory Arthritis Centre at Guy’s and St. Thomas’ NHS Foundation Trust. This research has been funded by the Guy’s and St. Thomas’ Charitable Foundation. Patient input has guided all the initiatives in the Inflammatory Arthritis Centre.

In 2003, we surveyed 700 rheumatoid arthritis (RA) patients to determine areas for development. A major theme emerged regarding work disability. We found that one in three of our RA patients were currently involved in paid work and of this group, 50 percent were having difficulties at work. Of those who were retired or retired disabled, 50 percent felt they had done so because of their RA. Thirty percent of this group said it would be helpful to discuss work issues with an occupational therapist. Based on this patient identified need, various research projects were developed to assist in preventing work loss.

Our Findings

There have been several interesting findings with this research on prevention of work disability. Firstly, we found that it is very important to screen for work disability with tools like the RA-Work Instability Scale (RA-WIS). This helps to identify RA patients who are at risk of work loss and assist in the provision of early, targeted intervention.

Secondly, we found that RA patients who have active disease (DAS28 of 3.81) and functional impairment (HAQ of 0.55) were more likely to demonstrate higher self-perceived work disability risk (RA-WIS > 10), although the variation in HAQ and DAS scores account for only 54 percent of WIS score variation.

In a study presented at EULAR 2007, we found that RA patients identified several needs to address work issues; including managing joint pain, fatigue, sleep, and household tasks. Interestingly, stress was one factor that was associated with higher disease activity, functional impairment and work instability. Therefore, we concluded that interventions aimed at improving work ability should target factors directly and indirectly related to the workplace.

These results directly helped conduct a parallel design randomised controlled trial (RCT) on the impact of comprehensive occupational therapy (OT) in RA patients at risk of work loss. We hypothesised that RA patients with increased perceived risk of work disability would benefit from specific client-centred OT intervention. Working RA patients with increased perceived work disability risk were identified by the RA-Work Instability Scale (WIS). Patients were randomised to OT intervention or usual care groups. Assessments were conducted at baseline and six months. The control group was offered OT after six months. The primary outcome was the Canadian Occupational Performance Measure (COPM), a standardised OT measure of function. Other outcomes included MHAQ, DAS28, RA-WIS, EQ-5D, VAS pain, EMS, VAS work satisfaction, VAS work performance, and days missed/month. Thirty two RA patients were recruited. The findings of this initial study demonstrate that comprehensive, timely OT intervention for those with increased perceived risk of work disability results in improved functional outcomes and, more specifically, work outcomes. Further longitudinal RCTs are required.

Alyssa Macedo
Specialist Occupational Therapist

Leisure activities and RA

For the Greek Aristotle, leisure was considered as something that provided intrinsic pleasure, meaning, and added value to life. It was performed for its own sake, not in consideration of any external rewards. In 1899, sociologist Thorstein Veblen associated leisure with high status. Only wealthy people could occupy themselves with non-productive consumption of time. Leisure was first viewed as a rare activity, and it was not until the middle of the 20th century that leisure became more acceptable and was not seen merely as an undesirable activity. Today, leisure is often regarded as reward for work, although there is no consensus of the actual definition of leisure.

Possibilities of active free time should be part of everyone’s life style, also of those suffering from rheumatic diseases. Occupational Therapist Ingegerd Wikström’s thesis explores the associated factors and assessment of leisure activities regarding people with rheumatoid arthritis (RA). Wikström completed her dissertation at Malmö University, Sweden, in 2006.
As the essence of life
According to Wikström, leisure activities are an essential factor for the sense of security and worthiness as well as for the feeling of freedom, value and satisfaction. Participation in leisure activities may be vital for preventing isolation, as well as providing a better self-confidence.

- Being able to freely choose leisure activities is an immensely important part of engaging in leisure. Giving up the most important leisure activity due to disease often results in a state of depression. The ability to participate in intellectual free time activities may protect cognition, and reduce the risk of dementia, Wikström says.

The onset of a chronic disease affects the ability to participate in leisure activities. Wikström’s studies show that 2/3 of the leisure activities are lost within the first seven months after the onset, leaving only passive activities available.

- This loss could be due to limited choices and time restriction imposed on the patient by the disease. But by adapting leisure activities to become more sedentary, RA patients try to overcome the obstacles caused by the disease, and they have been found to change free time activities frequently. The value of leisure activities is reduced if the activities are experienced as difficult to perform. By not being able to perform old free time hobbies the patients reduce their social network, Wikström explains.

The role of prevention
Decreased leisure participation may be a result from experiencing helplessness due to the outbreak of a chronic disease.

- Predicting such a decline is important since it may enable preventions, Wikström says.

The thesis indicates that compared to the control group, patients with RA are participating in significantly fewer leisure activities at the beginning of the disease, especially in outdoor life, gardening and individual sports. However, the patients can be couched individually or in a group to adjust to the situation.

- Advising them to perform the free time activities they used to do with some changes and adjustment or performing in shorter time intervals may reduce the fear of failure and the loss of active leisure possibilities, Wikström sums up.

Likely factors influencing loss of leisure activities among patients with RA are:

- High age
- The number of painful and swollen joints
- High Visual Analogue scale (VAS) pain
- VAS fatigue
- Morning stiffness lasting longer than 1 hour
- Health Assessment Questionnaire (HAQ) score
- Low level of education (vocational, secondary or primary school)

The AHP theses continue on the next page →
Think Positive on World Arthritis Day

Every year on the 12th of October, people from all around the world join together to make sure that their voices are heard and to raise awareness of arthritis/rheumatism, a disease that affects millions of individuals across the globe. World Arthritis Day has been initiated by Arthritis and Rheumatism International (ARI) in 1996 and is growing each year.

Since 2003, People with Arthritis/Rheumatism in Europe (PARE) Manifesto has been encouraging its member organisations to organise national and local events and arranged several activities on European level. Since the merge of PARE Manifesto and the EULAR Social leagues in January 2008, the World Arthritis Day activities are driven by the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe.

Each year highlights a special theme for the activities around this day. In 2007, the theme was Small things matter and a range of exciting projects that brought to life the small but important challenges people with arthritis face everyday was initiated. In 2008, we will focus on Think Positive – most people are aware that arthritis/rheumatism presents a number of physical problems, but the psychological challenges faced by people with arthritis/rheumatism are often overlooked. Our call to action is to ensure that people with arthritis/rheumatism are offered psychological support, as well as treatment for their physical symptoms. We also want to learn from people with arthritis/rheumatism, e.g., what they do to when they are feeling low, so we can share this with others in similar situations.

Passports and diaries
The limited time of consultation, the difficulty of remembering all the details since the last meeting with the doctor and the importance of establishing an open dialogue inspired us to develop a Health Passport. This is a personal health record that can be used as an aide memoir both when preparing for a consultation and during the consultation. Following the success of this project when it was piloted in Belgium, it is currently being rolled-out around Europe.

The Video Diaries are a series of short but powerful films recorded on reusable cameras. These demonstrate the impact arthritis has on people’s lives and how they are coping with these challenges. The Video Diaries have attracted great interested from the media in England where Arthritis Care was developing the pilot project in 2007. Other European countries are currently preparing their own national Video Diaries which will be edited together and presented at the EULAR booth at the EULAR Congress in Paris this year.

To help find out more about the psychological

AHP thesis:

Ingvild Kjeken has worked as an occupational therapist for 25 years. She now has a position as researcher at the National resource centre for rehabilitation in rheumatology at Diakonhjemmet hospital.

Participation, involvement and functional assessment in rheumatology care

Within rheumatology, there is a growing consensus that patients should be involved as partners in the clinical practice and research. Occupational Therapist Ingvild Kjeken addresses this issue in her thesis by exploring how to involve patients in assessing activity, participation, and rheumatology care. She defended her doctoral dissertation at Oslo University, Norway, in 2006.

- For the study, more than 1200 patients participated in clinical examinations, semi-structured interviews, and/or completed self-reported health status questionnaires, Kjeken says. The patients described a wide variety of activity limitations and participation restrictions, with household psychological support, as well as treatment for their physical symptoms. We also want to learn from people with arthritis/rheumatism, e.g., what they do to when they are feeling low, so we can share this with others in similar situations.

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To help find out more about the psychological
challenges and coping strategies of people with arthritis/rheumatism, we are conducting a “Think Positive” online survey on the WAD website (www.worldarthritisday.org). Built on the success of the 2006 and 2007 surveys, we would like to encourage people with arthritis/rheumatism and doctors in your country to complete the survey questionnaire – our aim is to have 50 to 100 completed questionnaires from each country.

National events
to the web
The World Arthritis Day website features all the material around the 2008 projects. An interactive European map is introducing the many activities taking place on and around 12 October in Europe – for more information, please visit www.worldarthritisday.org.

What activities are you planning on World Arthritis Day? We would like to hear about your events and add them on the website – thank you for helping us to make World Arthritis Day bigger and brighter in 2008. For any questions, please contact Birte Glüsing (Birte.Gluesing@eular.org) or Florian Klett (Florian.Klett@eular.org) at the EULAR secretariat.

Sandra Canadelo, Portugal
The Chair of the Standing Committee of PARE

World Arthritis Day projects in 2008 are supported by educational grants from Pfizer and Wyeth Europa.

The aims of World Arthritis Day are:
• To raise awareness of arthritis in all its forms among the medical community, people with arthritis and the general public.
• To influence public policy by making decision-makers aware of the burden of arthritis and the steps which can be taken to ease it.
• To ensure all people with arthritis and their caregivers are aware of the vast support network available to them.

Sandra Canadelo is pleased with the Health Passport. The Belgium Health Passport was launched by RheumaNet and CLAIR in March 2008.

EULAR awards up to 10 bursaries for educational visits to Allied Health Professionals other than physicians working in the field of rheumatology to enable them to make an educational visit to colleagues in another EULAR member country. The amount of each of the bursaries is between €750 and €1500. The total annual amount granted is €7,500. The objective is to improve the standard of research and care and to foster collaboration across clinical units in Europe. The deadline for applications is the 31st of March 2009. Applications should be submitted by e-mail to the EULAR Secretariat at eular@eular.org. Applications should include a CV with the date of birth, objectives of the educational visit, a budget, a written confirmation from the host hospital or institute, and the tentative time frame of the training visit. The application form and the contract to be signed with terms and conditions are available at: www.eular.org/myUploadData/files/AHP_EducationalVisitContract.pdf

Recipients are required to submit a report to the EULAR Secretariat after the visit, focusing on the results that have been achieved.

Educational visit report to Diakonhjemmet Hospital

My visit to Norway was a success. We are planning a study in cooperation with the Swiss Patient League for Ankylosing Spondylitis (AS) to evaluate the effectiveness of the exercise groups offered by the AS Patient League and lead by physiotherapists throughout Switzerland.

Therefore, I applied for an educational visit grant to the research group of Kare Birger Hagen, PhD, RPT at the National Resource Center for Rehabilitation in Rheumatology (NRRK) at the Diakonhjemmet Hospital in Oslo, Norway.

The objectives of the visit were to examine with experienced researchers in the field issues and methodological questions for further research with AS patients based on the available evidence; to receive an insight into a current intervention study with AS patients and to discuss practical issues and to explore collaborative research projects.

The programme of the visit

On the first day, I was given a short introduction to the research unit and its organizational structure by Kare Birger Hagen. Then, Anne Christie and Rikke Moe presented me the concept of “overviews of overviews”, i.e., umbrella reviews that systematically evaluate methodology and findings of systematic reviews. Therese Bjor then gave me an insight into the exciting approach of their rehabilitation unit. The main part of this day was dedicated to conversation with Hanne Dagfinrud, PhD, RPT, who has conducted several Cochrane reviews about physiotherapy in ankylosing spondylitis patients. Exercise is beneficial for AS patients, especially in spinal mobility, but generally not in other variables, such as pain or fatigue. We discussed the consequences of the current evidence extensively and exchanged ideas about focus of further research and adequate study designs.

The second day, Ingvild Kjeken, PhD, ROT and I travelled to Lillehammer where an inpatient trial with AS patients is currently going on. Ingvild is the primary investigator and regularly visits Lillehammer to meet with the local responsible researchers. We received a warm
welcome from the Coordinating Physiotherapist and Occupational Therapist at Lillehammer’s hospital, Ingvild Bo and Aud Ronningen. The practical problems and the solutions that have to be found provided a picture of real-life research.

On the third day, Heidi Zangi presented me vitality training, a patient education programme based on Gestalt therapy and dealing with the individual perceptions, emotions, and beliefs of RA and fibromyalgia patients. I was invited to give a lecture to the staff about my joint protection research, followed by lively and interesting discussions. There was then time to continue work on my planned RCT and substantiate outcomes and interventions. Hanne, Kare Bigger, and I explored and agreed on future collaboration, and we will meet again at the EULAR Congress.

Fruitful cross-national co-operation
The presentations of the interesting research projects and the insight into the rehabilitation services at Diakonhjemmet and at Lillehammer were perfect opportunities for exchanging notes about common ground and differences. Additionally, I had the pleasure to meet Gerd Jenny Aanerud personally, the patient research partner at the NRRK - probably the first in the world employed with public money. Thanks to her lecture at the EULAR Congress 2005, I then integrated a patient research partner in my own research project.

My warmest thanks go to Hanne Dagfinrud, Ingvild Kjeken and Kare Bigger for sharing their time, experience and ideas with me, to help develop an exciting protocol for my research. I’m thankful for their enthusiasm.

Last but not least, this educational visit was expanded into socio-historical education, as I enjoyed the unique opportunity of celebrating Norwegian’s National Day on 17th of May.

Karin Niedermann, PT, MPH,
Research Fellow in the Clinical Research Unit of the Department of Rheumatology and Institute of Physical Medicine in the University Hospital Zurich, Switzerland.

Great Ormond Street Hospital for Children in London
Many thanks to EULAR for making my educational visit possible with a grant. My destination was the Great Ormond Street Hospital (GOSH) during 16th and 27th June. Specialist Physiotherapist Sue Maillard organised a programme for me which included observation of juvenile dermatomyositis, benign hypermobility syndrome (BHS), juvenile scleroderma (with pulmonary arterial hypertension = PAH) patients.

In the first two days of my visit, I was to observe the scleroderma patients with PAH. I visited PAH centres of GOSH and Royal Free Hospital. In Royal Free Hospital, I also participated in a meeting on PAH, was organized by Dr. Carol Black, and took part in a three day meeting which contained multidisciplinary approaches in different rheumatic diseases. These meetings were very informative. I learned about multidisciplinary aspects of different rheumatic conditions; parameters of diagnosis, importance of MRI scanning, physiotherapy, occupational therapy, podiatric and psychological aspects, and so on.

Inspiring commitment to treatment
During the second week of my visit, I observed a great number of patients with Sue and her physiotherapy team members, Haeley Mato and Jennifer Armstrong. The team met at Sue’s office on Monday morning to decide the schedule for the week. Haeley and I assessed two patients with BHS. A group exercise programme was organized for patients in the afternoon of the same day. Patients who participated in the exercise programme had been diagnosed with BHS, scleroderma, and dermatomyositis. This programme was built on the basis of applying an hour for each session and it has been carried out twice a day in every two weeks for many years. This exercise programme included strengthening exercises with weights, flexibility, endurance, and balance parameters of the physical fitness. It was effective for the patients. After seeing such an exercise programme, I started planning a similar programme for my paediatric patients in Turkey.

I visited the BHS clinic on Wednesday morning with Sue, Dr. Hasson and Dr. Graham, and the dermatomyositis clinic on Thursday morning with Sue and consultant rheumatologists. They investigated three patients with BHS and four patients with dermatomyositis. For me, it was the first time I had took part in such a clinical study regarding patients with BHS dermatomyositis. I learned different assessment methods and exercises regimens regarding these diseases. I performed control evaluations of the patients who were assessed before. In my opinion, it is necessary that the same value and treatment should be given to patient groups also in my country.

There was a great communication between all of the team members; consultant rheumatologists, physiotherapists, occupational therapist and nurse specialists, it was so impressive. They were organising patient meetings twice a week and discussing the patients’ status. I felt that in Turkey, we need to develop a multidisciplinary team approach for our rheumatic patients just like the GOSH team.

I would like to thank Sue for her friendly and informative attitude. I felt at home in GOSH. Further, I want to thank Dr. Gerry Coghlan and Nurse Specialist Claire Das from Royal Free Hospital and Nurse Specialist Yvette Flynn and of course Haeley Mato and Jennifer Armstrong from GOSH for their hospitality.

Edibe Yakut, PT, PhD
Hacettepe University School of Physical Therapy and Rehabilitation, Samanpazari Ankara Turkey

More information about health professionals at Great Ormond Street Hospital (GOSH)
www.ich.ucl.ac.uk/health_professionals/
EVENTS & NEWS

The EULAR Scientific Committee held its meeting in Paris in March 2008 finalizing the congress programme 2008. John Verhoef, Jackie Hill, and Peter Oesch participated as the official AHP representatives in the Scientific Committee. At this meeting, the best scoring abstracts were selected for oral presentation in the abstract sessions. A total of 180 AHP abstracts were submitted for Paris among which 72 were on the topics “practice and clinical care” and 108 on “scientific topics”. This is, in comparison to previous congresses, a shift towards the scientific topics. AHP abstracts will be presented in their own AHP abstract session held on Thursday the 12th of June from 10:15 to 11:45 as well as in scientific abstract sessions. We are convinced that we have a very interesting programme in Paris and hope it will attract a lot AHPs to the congress. For detailed information including oral presentations of submitted abstracts, see www.eular.org.

AHP poster sessions
Please notice the AHP poster sessions on the topics “practice and clinical care”. These are organized according to the different Allied Health Professions. The AHP poster sessions will be held in the exhibition area with the following schedule:
- Thursday: Physiotherapy & miscellaneous forms of clinical care
- Friday: Nursing
- Saturday: Psychology/social science & Occupational Therapy.

The AHP abstracts submitted for the scientific topics will be displayed in the scientific poster sessions.

The AHP programme 2008 in Paris

The Palais des Congrès is spread out over three levels with amphitheatres, exhibition halls and conference rooms.

The AHP preliminary programme 2008 in Paris

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<td>Pregnancy and rheumatic diseases</td>
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<td>Patient partnership, could we do better?</td>
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EULAR Award for AHP Abstract

We were delighted to hear that our AHP abstract “Validation of the educational needs assessment tool in four rheumatic diseases” by M. Ndosi, J. Hill, A. Tennant, C. Hale, B. Hardware and A. Adebajo, has been selected to win one of the twelve EULAR Abstract Awards in 2008.

The award will be presented to Mwidimi Ndosi at EULAR’s Congress in Paris. This study was conducted with the help of a grant from Arthritis Research Campaign in the United Kingdom.

Jackie Hill
Arc Senior Lecturer in Rheumatology Nursing

Nurse Mwidimi Ndosi will receive the award at the opening ceremony in Paris.

The AHP research grant 2008

In 2008, five applications for a research grant were received and sent out for peer review by three independent reviewers. The grant 2008 to 2011 was awarded to Dr. Tanja Stamm from the Vienna Medical University, Department of Internal Medicine III, Division of Rheumatology, for her project titled “Evaluation and development of clinical outcome measures and instruments in Systemic Sclerosis from the perspective of patients”.

Since 2003, EULAR has awarded research grants for health professional research projects in the field of rheumatology. Despite an increased effort to advertise the AHP research grant, for two successive years 2006–2007, EULAR has received only two applications per grant. A survey among AHP researchers revealed that distributing this grant over three successive years is a major disadvantage, which prevents them from applying for it. It was, therefore, decided by the members of the EULAR Executive Committee in their meeting in October 2007, to offer an annual grant for an AHP research project of maximal € 30,000 without setting a time limit. Grant application forms are available at www.eular.ch.

EULAR Congress from 10 to 13 June 2009 in Copenhagen

The Programme Committee of the Allied Health Professionals in Rheumatology encourage their colleagues to submit session proposals for the Allied Health Professionals programme at the annual EULAR Congress. This has been again a great success. We have received 13 proposals that are currently peer reviewed by members of the Allied Health Professional Programme Committee and, if accepted, incorporated in the programme 2009 in Copenhagen.

We will use the same process for the programme 2010 in Rome. Submission date will be the End of April 2009.

Proposals can be submitted for a symposium or a workshop. A workshop should emphasize interaction. Symposia and workshops should not exceed four speakers. An international faculty, predominantly European, is expected. The duration of both will be 90 minutes. If you plan to have three speeches, consider 3 x 25 minutes plus 15 minutes chair time; with four speeches plan 4 x 20 minutes plus 10 minutes chair time. The submission form can be downloaded from http://www.eular.ch/prgrm_committees_health_professionals.cfm.

Do you have good news for the newsletter?

Since 2000, AHP newsletter has functioned as the main information channel of the Allied Health Professionals in Rheumatology within EULAR. The newsletter is published twice a year featuring the work of Allied Health Professionals and all aspects of multidisciplinary collaboration in rheumatology.

Let us know about recent AHP dissertations, health professional projects, research plans on AHP-fields (nurses, occupational therapists, physiotherapists, podiatrists, social workers and psychologists). Also news concerning the multidisciplinary development on the European level would be an interesting theme or an interview with a specialist on AHP approach.

The web link www.webropol.com/ahpsurvey.net will bring you to a query. By replying to the query you can contribute to the content of coming issues and give your views as a health professional about the most interesting matters in the field of rheumatic diseases.

Please answer the questionnaire by the 29th of August 2008.
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