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From the editorial secretariat

The HP Committee has urged European HPs to start their own national societies and offered them a smooth beginning. EULAR has witnessed a positive boom in the number of new national HP member associations. Although health professionals see the benefits of interdisciplinary co-operation, some justified questions emerge at times on the necessity to build a formal association. Do we really have to invest our own time and willpower in running a national HP association after working hours? Why not just participate in EULAR congresses, build personal networks and gather knowledge on your own? Isn’t the administration of an association rather complicated, who helps with the applications and plans fund raising, the seminars and happenings of the society?

For example in Finland, the Rheumatism association has promoted the need for a national HP association for more than 20 years. So far we have had poor luck. Finns tend to take these things very seriously and many HP enthusiasts have pondered thoroughly whether they have the means and energy to run an independent association based on rheumatology while dealing with the same issues all day long at work. Once again the people, in this case the HPs, made it happen by themselves – out of need.

**Proven experience from Northern Finland**

For the past 13 years, close to the Finnish Lapland, an association has been in full operation called “the MSD professionals of Northern Finland” with about 50 members. The founding board of the society knew each other already from the same rheumatology unit and they wanted to maintain the established link within the unique professional entity even when the activities were reorganised and the unit itself was closed.

The association kept the professionals in contact, gave a structure for the work and helped them to cope with the changes in the health care system. Many of the members were the only professionals specialised in rheumatology at their new working places, and that was one of the main reasons why the quality time spent at the association grew to be so vital. Running the association became their professional hobby and a way to enjoy and have fun while deepening their professional toolkit.

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**Surplus HP value and mutual support**

The HPs at Northern Finland have valued greatly the safe harbour for professional peer support, venting and backing provided at the association and the possibility to mainstream their every-day working skills. As the past chair of the association said about working together “you do not need to reinvent the wheel time after time, but you can come up with new spear parts or modified working methods to keep the wheel running.” The chance of evolving into a true professional with commonly shared experience is something to hold on. Here, the tacit knowledge becomes HP knowledge which eventually turns into guidelines and routines of state-of-the-art practise.

The ties to the local patient organisations have always been tight and self-evident in the North. Co-operation helps to encounter the person with MSD as an equal human being with feelings, guiding to provide the kind of treatment you would like to get if you were the patient. Nowadays, many of the early activists are already retired or are soon retiring and the association could use an energy boost to keep on going. That is why the MSD-professionals of Northern Finland want to see if the association can have a future as a national society covering the whole nation. For once, the roots and traditions would come from the North were even the long distances have not prevented from attending the meetings. The Rheumatism association is pleased of this development to say the least and is helping out in the process of becoming a nation-wide HP society. Much emphasis is laid on web-based meetings and national seminars as well as establishing easy-going network through the country.

**Mikko Väisänen**

Editorial assistant of the EULAR HP News Planner at the Finnish Rheumatism association concentrating on services for people with rare rheumatic diseases. Also a member of the development group of the Rehabilitation institute Apila in Finland.

*Musculoskeletal conditions and disorders = MSD*
Likewise, we inform you about the HP scientific programme for Madrid 2013.

This issue of the EULAR HP News offers reflective insights to the EULAR HP work and research. First of all, we introduce to you the HP chairperson-chair Sue Oliver, who reveals her goals in her coming term. Heidi Zangi explains what mindfulness and Vitality Training Programme (VTP) could mean as a tool for interdisciplinary teamwork in rheumatology. We are especially happy to tell about the latest developments of the Portuguese health professionals who proudly organised their first health professional meeting in Rheumatology. Portugal and many others hope soon to join the EULAR HP family just like newcomers Ireland and Spain. We also cover the latest updates on the EULAR HP member campaign which received many thanks in the Berlin congress. As part of our co-operation with the US-based colleagues, we present a perspective on the role of sleep in pain management provided by the Association of Rheumatology Health Professionals (ARHP). Remember also to take part in the survey of the EULAR scleroderma health professionals’ network (EUSHNet).

As inspiration to all European HPs, we have a two educational visit reports telling about fruitful expeditions to Leeds and Leiden. Next year, EULAR will offer 10 grants for educational visits, more information about the application procedure in this newsletter.

Pleasant reading moments with EULAR HP news

“Sorry we have just outsourced consultation on lower back to Asia. However, the actual treatment of the back is still under competitive bidding until June 2013.”
Sue Oliver in brief

I am an independent Nurse Consultant in Rheumatology and fellow of the Royal College of Nursing. Initially, I set up a new clinical nurse specialist role in a hospital in the South West of England but after years of working at the hospital I made a decision to start my own independent nurse consultant post.

I have been working as an independent nurse consultant for the last nine years. This role has provided me with a wide range of interesting projects alongside my clinical practice. Much of my work has involved working clinically within the National Health Service in the UK whilst exploring with the teams to identify ways of re-designing their service. Other activities included working as an advisor or expert panel member for projects for organisations such as the Department of Health and the National Institute of Health and Clinical Excellence. During this time, I am particularly proud of my time working as Chair of the Royal College of Nursing Rheumatology Forum and also my office as Chief Nurse Advisor for the National Rheumatoid Arthritis Society (a patient organisation).

Introducing the HP chair-elect

I am excited about being nominated and voted in as Chair Elect of the EULAR HP Committee. I have been attending EULAR as a delegate for many years and thoroughly enjoyed actively participating in the congress. Over the years, I have also seen how the Standing Committee have been so committed to raising the profile of health professionals (HP) at the same time as developing a congress programme relevant to the needs of HPs.

It is a daunting task and I am very aware of the excellent work that Thea as Chair and Kåre as vice-president have undertaken during their term of office. There has been much to learn and I am having a very rapid training programme thanks to the patience of both Thea and Kåre. There is also a fantastic team of committee members and the wider EULAR family – all of whom have been so helpful in advising me through these early days as a member of the Standing Committee.

The HP Standing Committee

Standing Committee of Health Professionals in Rheumatology is made up of a number of groups and a range of dedicated health professionals who support this work. The HP Standing Committee has set up a Scientific Sub-committee, Educational Sub-committee, and Communication Sub-committee. All three of these groups have separate meetings but also participate in the HP Standing Committee’s yearly Meeting during the EULAR congress.

The HP Scientific Sub-committee

This committee is very busy with a number of tasks but have an active role in working with the wider EULAR Scientific Committees to plan and provide a congress programme each year. Please find more about the next years Scientific HP programme on page 19.

The HP Education Sub-committee

This group has run the Teach-the-T eachers Course – led by John Verhoef who has dedicated a lot of his spare time to organising and running this course. I was delighted to have participated as a ‘teacher’ at the last course in September this year in Leiden. It was a real pleasure to work with the ‘students’ who will return to their countries to deliver an educational programme based upon the resources and presentations in which they have participated. I expect they will be the new committee members of the future as they progress their knowledge and expertise in their countries and return to EULAR to share some of their evidence from their work.

The interdisciplinary quiz on health professional teamwork was welcomed with interest by the congress delegates in Berlin.
The HP Communication Sub-committee

This committee is in charge of publishing this EULAR HP Newsletter twice a year. The spring edition is a printed edition which is distributed at the EULAR Congress. The Sub-committee also plans the HP stand as a joint meeting place for HPs during the congress, undertakes HP flyers and procures other materials and runs the EULAR HP member campaign (more on page 8). The Sub-committee carried out the first web-survey on the functions and services of the national HP member associations last year.

One of the tasks is to update the e-mailing list of HPs attending the EULAR congress every year. So far there are about 2000 HPs on the mailing list. The national HP societies update their own local mailing lists which are a vital link on the national level.

As the chair, I wish to enhance on-going communication strategies with all EULAR delegates where possible. Increase wider HP participation, new members and national presence, in the full scope of the congress programme, proposals and working group representation.

Task Forces

There are also task forces that include working on proposals that have been endorsed by the EULAR Executive Committee and funded to carrying out specific tasks. Some examples this year include the recommendation on the role of the nurse in caring for patients with inflammatory arthritis and recommendations for the non-pharmacological management of patients with Osteoarthritis of the knee and hip. I have participated in both these projects. If you are invited to participate in such work in the future I really hope you will consider taking part.

Future structure of the HP Committee to be discussed

The HP Communication Sub-committee waved for World Arthritis Day supporting the PARE’s campaign “move to improve”.

The EULAR Standing Committee of Health Professionals in Rheumatology (ESCHPR)

Scientific sub-committee

Educational sub-committee

Communication sub-committee

EULAR Standing Committee of Health Professionals in Rheumatology endorses interdisciplinary collaboration in the treatment of rheumatic and musculoskeletal diseases in Europe. The Committee was established in 1989 as a European platform for cooperation and shared information among the different health professionals working with rheumatology. The Committee encourages HP research and works also to improve the patient’s role as the key expert of his/her own treatment.

Communication and your opportunities to be involved in the work of EULAR relies upon us hearing from you but also in your knowledge of what activities are going on through the EULAR HP Committee.

Here are some suggestions about how to keep informed.

- Review the website regularly for new information on activities and work streams
- Make sure you have registered to receive the electronic newsletter which is full of information and time lines for specific activities
- Join one of the Study Groups (Further information in the next HP News)
- Communicate with your country president (if you are not sure who represents your country on the EULAR HP committee – look it up on the website)
- Visit the EULAR HP stand at the congress and meet some of the committee members
- Submit proposals (again see the website or emails for further information) for future congress and get actively involved.
- If your country/national HP association is currently not represented in the HP network of presidents – read on page 8 how to become a member of EULAR.
My EULAR vision

EULAR is an organisation that represents all members of the multidisciplinary team (e.g. doctors, nurses, occupational therapists, physiotherapists, psychologists, social workers, nutritionists and podiatrists, practitioners, researchers, and people with musculoskeletal conditions) across Europe. EULAR has important duties such as being active in raising areas of concern or need in European health and social care policy developments and encouraging research and translating this data into daily clinical care. Each year EULAR provides a congress - this year in Berlin and next year in Madrid (2013) - offering leading edge scientific evidence, educational opportunities and European networking.

In my view, health professionals and people with RMD working collaboratively as part of a multidisciplinary team (MDT) are vital for high-quality and cost-effective care. However, I do see that there are many challenges ahead; firstly, we need to work together to encourage equity of access to MDT care across the European Nations. But secondly and probably more importantly, we need to be mindful of the financial challenges and need to ensure that the resources of the MDT are used in the most evidence-based way. Each of the country members will be experiencing different challenges to their health care services and we must find ways of sharing expertise and innovation. Part of this will mean that we need to be our own hardest critics and challenge traditional working models and explore ways of enhancing patient empowerment and reducing costly ineffective care where ever we see it. By doing this we will be able to build upon our much valued role and important resource for patient care.

There is much that has been achieved since HPs became recognised within EULAR in 1989. But there is much more still to achieve for HPs. I want to convey my thoughts in the hope we can all work together to achieve some exciting outcomes! I would really like to hear from you whether you think these issues are the right ones to work upon during my term of office. The areas to consider are:

HPs at the EULAR Congress

I would like to see the congress HP sessions increase in number in the next years and continue to work effectively with our PARE colleagues and increase our contribution to the medical sessions at congress. During my time as Chair, I would like to see the number of congress HP sessions grow, achieve their aims and encourage the profile of HPs across Europe to grow in number, profile and contribution to care. I aim to increase the number of HPs attending EULAR Congress. So far there are about 400 to 500 HP delegates yearly. Also the introduction of formalising Study Groups is a very exciting new opportunity for HPs.

Study Groups

As some of you may be aware, there have been informal networking meetings arranged for a number of years now to enable different disciplines to interact and consider specific issues and plan strategies for future development and support of others within EULAR. The EULAR’s Executive Committee now ask that these informal groups are more clearly defined and that they understand more about the work of the groups. According to the new plans, these groups will fall into the category of a Study Group. These meetings need to be more formally documented and recognised by the EULAR Executive Committee. If the study group is approved it will have a lead co-ordinator, a title, a description of the aims of the group and a short annual report. EULAR will simply offer access to a room for the annual meeting at congress – there will be no funding attributed to these study groups. This is a good first step because the interests of these groups will be more widely communicated and help to recognise the early work that many of you as delegates of congress undertake. It also means that there are opportunities over time to develop new study groups. This approach will help the HP Committee to negotiate access to rooms for these meetings each year at congress and hopefully early on in the planning so that the programme will then show new attendees where the meetings are being held and allow them to join but also allow everyone to plan their attendance accordingly for congress.

Use of awards and bursaries

EULAR is generous with the awards and bursaries that are available for HPs. I hope that we can spread the word further about the range of awards and bursaries that are available and encourage individuals to apply for them. I encourage you to look at the website and see if there is something that can help you develop your knowledge and expertise within your field of practice. Read more about the educational visit bursaries on page 16.

Non-congress-related issues

The HP Committee has for years worked hard to increase the number of national representations. Subject to the decision of the Executive Committee in June, we are

EULAR Health Professionals News

6
At the EULAR General Assembly of Delegates 2013 in Madrid, taking place on 12 June at the FERIA DE MADRID, elections of the EULAR President-elect 2013-15, the EULAR Vice-President representing health professionals as well as the Vice-President representing PARE for the term 2013-17 will be held.

According to the procedures set forth in the by-laws of EULAR, the EULAR Secretariat has asked the national EULAR HP member associations to make nominations for the position. The HP presidents have received more information on the matter. The nomination proposals must be submitted by 31 December 2012 at the latest.

EULAR has also established a Search Committee led by Prof. Paul Emery, advising and assisting the search process for candidates. The EULAR Executive Committee will make a preliminary review of the received nominations at its meeting in March 2013. All nominations will be presented to the General Assembly as stipulated by the EULAR by-laws.

Nomination of the HP vice-president 2013-2015 for EULAR Executive Committee

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Next stage as the chair-elect

I have highlighted what I feel are the areas to work on but I do hope to hear your views into your experience of attending congresses, participating in committees etc. over the years and what vision you have for how the HP Committee should develop. Although my full term of office is four years in actual fact there is little time to make a serious difference and build on the success of previous chairs. I have one year as chair elect, two years of working as Chair and one year as Past chair. So...

EULAR HPs need YOU. Please get involved, participate, ask questions and communicate with us. We need to hear your views.

Sue Oliver
Chair-elect of the EULAR HP Committee
Independent Nurse Consultant in Rheumatology
sue@susanoliver.com

Soon to have 13 members – our most recent proposed new member candidates are Spain and Ireland – Welcome! We need to be aware that there are almost 50 European countries depending how one determines Europe. So we have much to do if we are to build upon previous Chair and Vice President’s work in building the number of countries and to be truly representative of the European health professional countries.

As mentioned, it would be ideal if we can continue to increase our country membership but also find ways of supporting countries that are struggling to develop their organisations or raise their profile. If we can provide more of a supportive approach to our national members then there are added reasons for others to wish join the EULAR HP family. There are also some very challenging times ahead with the political and economic climate, potentially threatening research and development with all fields of healthcare.

We need to identify strategies to support national HP presidents facing specific challenges they experience within their community offering expert resources within the EULAR family.

Dr. Past HP Chair Tanja Stamm (in the middle) became an honorary member of EULAR at the congresses opening ceremony in Berlin. Also in the picture Dr. Angela Zink, EULAR President Prof. Maxime Dougados, and Prof. Paul-Peter Tak.

For the first time, EULAR presented awards for altogether three top health professional research abstracts. The awards were given to Karin Magnusson (Norway) on “No Prospective Association Found Between Obesity and Chronic, Widespread Musculoskeletal Pain in a Population-Based 20-Year Prospective Follow-Up Study”, Michaela Stoffer (Austria) on “Development of User-Focused Standards of Care for Rheumatoid Arthritis and Mwidimi Ndosi (UK) on “Clinical Outcomes of Nurse-Led Care for People with RA: A Multicentre RCT.”
The successful member campaign

The EULAR’s Health Professional member campaign gained a lot of positive attention at the Berlin Congress. Many national delegates visiting the HP stand were keen on hearing more about the procedure of becoming a EULAR member. Please get acquainted with the 5 step plan on how to establish a national HP society and become involved with EULAR. Contact us for further information.

EULAR seeks more national health professionals (HP) organisations to become member of EULAR and participate in the work of the EULAR Standing Committee of Health Professionals in Rheumatology. All interdisciplinary health professional organisations specialised in the care and treatment of rheumatic and musculoskeletal diseases in European countries are welcome to join in.

EULAR has 11 health professionals associations as members:
- Associazione Italiana Operatori Reumatologici Professionali - AIORP
- British Health Professionals in Rheumatology (BHPR)
- Bulgarian Association of Health Professionals in Rheumatology
- Czech Association of Health Professionals in Rheumatology
- Danish Interdisciplinary Forum (DIRF)
- health professionals in rheumatology Switzerland (hpr)
- Netherlands Health Professionals in Rheumatology (NHPR)
- Norwegian Interdisciplinary Organisation in Rheumatology (NIOR)
- Serbian Association of Health Professionals in Rheumatology (SAHPR)
- Swedish Rheumatology Forum (SveReFo)
- The Romanian Society of Medical Partners for Rheumatology (RSMPR)
- 3 new national HP societies waiting for the ratification of the EULAR General Assembly

EULAR President Prof. Maxime Dougados congratulated the HP Committee for recruiting new HP national associations to join EULAR.

Motivation for becoming a member

EULAR currently includes 45 scientific member societies, 35 patient organisations and 11 health professionals associations in EULAR. New, committed organisations from the health professionals’ community in Europe would enhance our professional network and are therefore welcome. In addition to the inclusiveness of EULAR, consider these advantages as motivational factors towards membership:

- Receive first-hand information about and get involved in EULAR’s research and educational programmes designed for the needs of health professionals in rheumatology, such as the educational visits programme or the annual research grant. The objective is to improve the standard of research and care in health professions and to foster collaboration across clinical units in Europe.

- Delegate a representative of your organisation to work in the EULAR Standing Committee of Health Professionals in Rheumatology and actively contribute to shaping health professionals activities within EULAR. The committee, headed by a chairman, discusses on-going projects and new proposals to the EULAR Executive Committee, initiates and shapes ideas for the health professionals’ programme at the next annual EULAR congress, and reviews membership applications of national HP organisations. The committee, through its chair, also closely interacts with the other Standing Committees dealing with scientific, clinical, and patient matters. Each year, the EULAR Standing Committees hold their annual “business” meetings on the occasion of the EULAR congress.

- Make your national association heard on the European level by attending the EULAR General Assembly of our member organisations each year, where all sections of EULAR report on their activities, where constitutional matters are decided and elections to Executive Committee positions are being held.

- Enjoy the inspiring exchange with colleagues during the annual EULAR Congress where EULAR health professionals are operating a booth as a lively gathering point for health professionals. The congress is also an ideal platform for promoting the national association’s work as well as interacting with other health professionals from both EULAR member organisations and elsewhere.

EULAR Health Professionals News
Five steps to get involved for a national HP activist

1. If a national interdisciplinary health professional organisation already exists in your country, please find out first whether this organisation has a guest representative in the Standing Committee of HPs. If so, please contact this person regarding your involvement in EULAR.

2. In case there is no organisation representing health professionals in your country, you can establish a national organisation first. Bear in mind that this organisation’s bylaws should be in accordance with the EULAR bylaws. You can obtain the bylaws from the EULAR Executive Secretariat, contact: eular@eular.org.

   Importantly, this national organisation should represent different health professional groups (such as nurses, occupational therapists, physiotherapists, podiatrists, nutritionists, social workers, psychologists, and others) and should have a clear multi-/interdisciplinary perspective. All the professional groups mentioned above do not have to be represented in the organisation, but an open attitude towards all health professionals in the organisation is required.

3. Fill in the application form which you can also obtain from the Secretariat together with a letter stating that your organisation wants to join EULAR as a health professional organisation representing your country. Submit this application form to the EULAR Secretariat.

   The General Assembly meeting, held once a year before the annual EULAR Congress, will put your application and acceptance within EULAR to the vote.

4. When your organisation is a formal member, the person representing this organisation will also have a right to vote in the General Assembly.

5. The president of the national organisation will usually represent the organisation as delegate in the EULAR Standing Committee of HPs.

   In the process of establishing a national organisation and even before this, the Committee welcomes any health professionals interested in founding a national organisation to become a guest representative in the EULAR Standing Committee of HPs. As a guest representative you are then welcome to participate in the meetings of the Committee and in other activities within EULAR. In this case, please contact the Chairperson of the Committee, Dr. Thea Vliet Vlieland, T.P.M.Vliet_Vlieland@lumc.nl.

More information available at: www.eular.org/st_com_health_professionals.cfm

Belgian delegate Thijs Swinnen was interested in finding out in detail how to the Belgian HP association could join EULAR.

Research Nurses Andréa Marques and Ricardo Ferreira from Portugal plan to start a HP association. Andréa also was the winner of the interdisciplinary quiz held at the HP stand.
The first ReumaCare meeting took place in the beginning of June 2012 at Coimbra, Portugal. It was organised by the Coimbra Rheumatology Association (ARCo) and the nursing team of the Rheumatology Department of Centro Hospitalar e Universitário de Coimbra (CHUC, EPE). This meeting was scientifically supported by the Portuguese Rheumatology Society (SPR) and EULAR vice president, Prof. Kåre Birger Hagen.

This was the first multidisciplinary event in Portugal, giving a starting point for HP interaction and development of patient education and disease management. In the past, only nurse-focused meetings have been organised mainly by the pharmaceutical industries. Of course these separate meetings have their important place. Around a hundred health professionals participated in the ReumaCare meeting, bringing together nurses – still as the majority – but also physiotherapists, physicians, and pharmacists and occupational therapists.

Promoting happiness
A very interesting and interactive talk that made everyone smile was given by psychologist Miguel Leite. His title was "Promoting happiness and optimism in therapeutic context". He explained an optimistic person’s health gains as well as provided tips and strategies to achieve this kind of well-being. He also stated the seven potentially deadly sins against optimism, which were according to him: perfectionism, vicious self-esteem, dependencies, inaction and self-imposed limitations, chronic stress intoxication, acute “exclusivities”, irresponsibility and pessimistic ruminations.

The main topics of the ReumaCare meeting:
• Rheumatology Nursing: History and Future
• Rheumatoid Arthritis (Diagnosis and Treatment; Health Education and Disease Management; Patients’ Needs; Physical exam workshop)
• Multidisciplinary Approach in Rheumatology
• Research in Rheumatology for Health Professionals
• Management of Chronic Musculoskeletal Pain (Evaluation and Interpretation; Non-Pharmacological Techniques)

At the end, the participants voted on the themes for the next ReumaCare. The following topics were chosen: promotion of functional autonomy, non-pharmacological strategies for pain relief, prevention of wounds, and treatment in people with rheumatic diseases.

Portuguese HPs entering EULAR
Portuguese health professionals have a long way ahead in the development of skills to provide organised and systematic patient education. However, we are very optimistic about co-operating with the EULAR Standing Committee of Health Professionals in Rheumatology because this could be an important step for the unification of Portuguese Health Professionals in Rheumatology.

Because We Care
Ricardo Ferreira, Clinical Research Nurse, MSc
Andréa Marques, Clinical Research Nurse, PhD student
Reumatology Department – CHUC-HUC, EPE

Nursing and Non-pharmacological HP technics
Consultant Nurse Rheumatology, Prof. Jill Firth from the University of Leeds was the special invited speaker. She gave two brilliant presentations. First, she provided an overview on the development of British rheumatology nursing. In the second presentation, she explored the role of the nurse in the core of the multidisciplinary team.

Another invited speaker was Prof. Rui Soles Gonçalves from the Centre for Health Studies and Research, University of Coimbra, who spoke about the research challenges and opportunities in Rheumatology for Health Professionals. Prof. Gonçalves also concentrated on systematic literature review about the non-pharmacological technics for the management of knee osteoarthritis pain.

The lecture was followed by a panel discussion focusing mainly on exercise and weight loss, but also on acupuncture, electromagnetic field, transcutaneous electric stimulation (TENS), low level laser therapy, and psycho-educational interventions.

Prof. Jill Firth (on the right) referred to psychological support, patient education, physical examination and disease management, courses on MSc level, high-quality research, the telephone advice lines and other nurse-led services.
The ReumaCare meeting was finished with a vivid and involving workshop on physical examination with the important collaboration of eight persons with rheumatic diseases.

EUSHNet - the EULAR scleroderma health professionals’ network

Please participate in the EUSHNET scleroderma care survey!

EULAR’s new initiative for HP-related scleroderma care is trying to capture what is happening across the EULAR member states. We believe that systems and even standards of care vary widely across states but to-date there have been no formal data describing what happens where. To address this, and as part of the overarching effort to improve non-pharmacological care for scleroderma patients, EUSHNet is conducting a comprehensive online survey to evaluate the existing state of the art for health professional practice in scleroderma across European countries. We are asking health professionals and researchers involved in non-pharmacological care and/or research for patients with scleroderma to share their experiences through the online survey.

The survey is wide ranging and takes approximately 20 minutes to complete and your input will help us tangibly improve non-pharmacological care for people with scleroderma.

The survey can be accessed by simply clicking on the link at http://goo.gl/uouXN

Your input is very important to us and will be kept strictly confidential (information provided will be used only for the purposes of this project). If you participate in this research and provide your email address we will notify you of the results.

If you have any questions, please e-mail Linda Willems at li.willems@maartenskliniek.nl or Els van den Ende at e.vandenende@maartenskliniek.nl

To find out more about the EUSHNet initiative visit www.eushnet.org or ‘like’ us on Facebook at www.facebook.com/EUSHNet

Anthony Redmond
Chair, EUSHNet
A group-based intervention: Vitality training programme on psychological distress in patients with inflammatory rheumatic diseases and fibromyalgia

How do people find the motivation for a lifestyle change? To bring about change is an aim of most interventions offered to patients with chronic rheumatic diseases. From clinical experience, we know that telling patients what they should do seldom alters behaviour. Change does not follow from a rational thought of what we think we ought to do or from trying. The paradox is that rational thought of what we think we ought to do or from trying. The paradox is that accepting what is, change is likely to come when we stop trying and become aware of and accept what is, change is likely to come about.

Awareness and acceptance

The Vitality Training Programme (VTP) is a group intervention that was originally developed and tested for persons with chronic musculoskeletal pain in the late 1990s and described in a doctoral thesis by Haugli and Steen (2001). I have had the privilege to work with one of the developers, Eldri Steen at the National Resource Center for Rehabilitation in Rheumatology (NRRK) at Diakonhjemmet Hospital in Oslo since the beginning of this century. Together, we have adjusted and implemented the VTP for persons with inflammatory rheumatic diseases. People with chronic musculoskeletal disorders and rheumatic diseases have collaborated in all parts of the development, implementation, and evaluation of the programme.

In the Vitality Training, the concept of “vitality” reflects that the VTP aims at strengthening the patients’ health promoting resources, their capacity to engage in the process of everyday living and continuation of a meaningful and valued life, rather than focusing on strategies to control or reduce symptoms. The word “training” implies that mental vigour can be trained as well as physical strength, and that this training, like other training modalities, is a process that takes time.

Awareness and acceptance are basic concepts in the VTP. The programme can be classified within the newer mindfulness- and acceptance-based behavioural interventions which have gained increasing interest in the recent years. One of the core aspects in these therapies is training in open-hearted moment-to-moment awareness to internal experiences, such as thoughts, feelings and bodily sensations, without judging or wishing things to be otherwise. According to Kabat-Zinn (1996), this is conceptualised as mindfulness.

Another aspect is the cultivation of self-compassion, i.e. kindness and care toward own experiences, seeing any thoughts, feelings and sensations that arise as part of the human experience rather than a sign of pathology, weaknesses, or limitations. It is believed that experiencing the present moment non-judgementally, openly and reflectively can effectively counter the effects of stressors, whereas excessive orientation toward the past or the future when dealing with stressors can be related to feelings of depression and anxiety. Shapiro (2010) says that acceptance is perceived to be the strongest mediator of human change and development. It is believed that if we can observe our thoughts and feelings by friendly acceptance without responding reflexively, we may gradually free ourselves from being controlled by automatic thoughts. Recent meta-analyses have documented that mindfulness-based interventions can reduce the mental distress that may accompany chronic conditions, including rheumatic diseases.

Read the whole article with the results and references at Ann Rheum Dis 2012 Jun; 71(6):911-17.
Narrow biomedical approach is inadequate

Although pharmacological treatment for patients with rheumatic diseases has developed remarkably during the last decades, existing medical treatments are not sufficient to cure or control all symptoms and disease processes. A broader understanding of the complex interaction between person and disease has evolved, and one has realised that a narrow biomedical approach is inadequate. How people respond to their illness and experience their quality of life cannot be explained by the severity of the disease and symptoms alone.

Several patients experience their condition as stressful. Furthermore, the need for long-term medical treatment combined with lifestyle changes may be demanding and challenge a person’s habitual coping strategies. How people cope with disease-induced stress and adjust to the changes can influence their vitality, life satisfaction, self-esteem, social interactions, and overall wellbeing. There is therefore a need for non-pharmacological interventions that enhance individuals’ physical and mental coping abilities and promote their adjustment to living with a lifelong disease.

The evaluation of the VTP has provided evidence for the health promoting effects of this mindfulness-based group intervention. The most important findings are probably the long-term effects of the VTP in persons with inflammatory rheumatic joint diseases. Rather than being targeted toward specific goal attainments, the VTP encourages non-judgmental awareness and acceptance of whatever emerges in the present moment, whether being pleasant or unpleasant. Participants are further encouraged to identify their personal values and resources and to find their own meaningful answers, and thus take greater responsibility for their life choices. This may have strengthened their sense of internal control. In a randomised controlled trial, the VTP participants significantly reduced psychological distress and fatigue and increased their emotional awareness and self-efficacy beliefs compared with the control group.

Motivation as the key

Motivation is important particularly in interventions that require active participation and personal effort. A key question is how people can be reached at the time they are motivated and in need for this kind of intervention. The majority of participants in our studies had relatively long disease duration and high disease impact in terms of psychological distress, pain, and fatigue, indicating that the VTP is most relevant for this group of patients. However, several participants asked why they had not been offered to participate in the VTP at an earlier stage, and further studies are needed to explore the effects of the VTP in persons with more recent onset disease.

Most people who enrolled in the VTP showed high commitment to the intervention. They attended between 8 and 10 sessions, and there were very few dropouts, indicating that it was feasible for those who enrolled. The VTP is not intended to be included in routine care, but as a complementary intervention for people who need to strengthen their abilities to respond to the stressful experiences related to their disease.

This research project has documented beneficial health effects of the VTP in terms of reduced psychological distress and fatigue, enhanced emotional wellbeing, self-efficacy and self-care ability in patients.

Peder Austrud, Diakonhjemmet Hospital
with inflammatory rheumatic diseases. The results show that the VTP is a feasible intervention that should be considered as a beneficial complement to existing treatment, particularly for people who experience heightened psychological distress and fatigue.

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Further reading:
Zangi HA, Hauge ML, Steen E, Finset A, Hagen KB "I am not only a disease, I am so much more". Patients with rheumatic diseases' experiences of an emotion-focused group intervention. Patient Education and Counselling (2011), 85: 419 - 424

Psychological distress is commonly reported in rheumatic diseases. The main outcome assessed in the study was psychological distress. This concept commonly refers to milder symptoms of depression or anxiety that do not meet the criteria for a full mood or anxiety disorder. Psychological distress has been defined by Ridner (2004) as a "unique discomfiting, emotional state, which an individual experiences in response to a specific stressor that results in harm, either temporary or permanent". The experience of distress occurs when individuals perceive a stressor as a personal threat which they are unable to control or cope with.
Pain Management and the Role of Sleep

The extent and experience of pain is influenced by affective, behavioral, and cognitive processes. Thus, there are numerous factors to consider in pain management; however, the role of sleep may be one of the most important. There is good evidence that sleep, pain, and depression form a tightly interconnected triad where changes in one of the three can impact the other two. For example, disturbed sleep can result in increased pain and contribute to changes in mood, while persistent pain can contribute to poor sleep and a depressed mood.

Sleep disturbances are common even in healthy individuals. The prevalence of insomnia in the U.S. population has been estimated to be higher than 10 percent, but people with chronic illnesses are at an even greater risk. A recent study reported that 23 percent of adults with arthritis experience insomnia. This same study found that those with arthritis and depression or anxiety were at the highest risk for disturbed sleep.

Conversely, sleep disruption can reduce pain threshold and contribute to other symptoms like fatigue, cognitive fog, and irritability, as well as diminished functioning and overall decreased quality of life.

### Waking up tired

Evaluating sleep in rheumatologic patients can begin with a single self-report item on intake or follow-up forms. We use the “waking up tired (unrefreshed)” item from the Symptom Severity scale that is part of the survey criteria for fibromyalgia. Responses suggesting disturbed sleep can be further explored by assessing the number of hours of sleep per night, ability to fall asleep, and waking patterns throughout the night. Further, some patients have other specific conditions that account for sleep disturbances, such as sleep apnea or restless legs syndrome, which should be evaluated and addressed when present.

Validated measures such as the Pittsburgh Sleep Quality Index or the Medical Outcomes Study Sleep Scale can be used in clinical practice for both initial evaluation and assessment of improvement posttreatment.

After considering the nature of the sleep disturbance, behavioral interventions may prove to be a low-cost and effective solution. To determine what behavioral changes might be needed, an assessment of general “sleep hygiene” can be conducted. Sleep hygiene refers to the practice of maintaining good habits that are conducive to sleep. Often, patients with chronic pain develop bad habits with regard to their sleep, such as taking long naps during the day, drinking too much caffeine to combat fatigue, or engaging in stressful activities too close to bedtime.

Once you’ve identified the problem behaviors, encourage your patient to make changes and set concrete, but easily achievable, goals. It can be helpful to reassure patients that millions of people experience sleep disturbances and that the good news is that sleep problems can be frequently addressed with behavioral changes alone. If patients do not respond to simple sleep hygiene interventions, a referral to cognitive-behavioral therapy could be a good next step.

### Brief sleep-hygiene checklist

- I get up and go to sleep at the same time every day, even on the weekends.
- I do not take naps during the day that last more than 20 minutes.
- I avoid caffeine, nicotine, and alcohol for at least six hours before bedtime.
- I do not exercise for at least four hours before I go to bed.
- I limit my liquids in the evening so I can reduce my need to use the bathroom.
- I have bedtime rituals such as brushing my teeth, setting the alarm, and reading a book.
- My bedroom is kept dark and at a very comfortable temperature.
- My bedroom is free of distractions (I do not watch TV or work on projects while in bed).
- I go to bed only when I feel sleepy.
- If I cannot fall asleep within 30 minutes, I get out of bed and do something relaxing.

Table 1 shows a list of behaviors generally considered essential for good sleep. These behaviors appear in a checklist format that can be adapted for use in the clinical setting.

### References

Digital motion capture systems and more at Leeds Musculoskeletal Biomedical Research Unit

I work as an associate researcher at Let People Move Research Institute in Arezzo, Italy. Prior to my visit to England, we planned a cross sectional study on patients with Patellofemoral Pain Syndrome (PFPS). In October 2012, I left for an exciting two week educational visit at the NIHR Leeds Musculoskeletal Biomedical Research Unit (LMBRU) which is Professor Paul Emery’s rheumatology unit located at the Chapel Allerton Hospital.

The aim of my visit was to gain further experience in the management of people with PFPS, especially to learn how to make a proper diagnosis using digital motion capture systems for movement analysis combined with the use of internal imaging (MRI and ultrasound).

HPs in action
My visit was arranged by Dr Anthony Redmond, and during the visit, I had the opportunity to witness an excellent multidisciplinary team work in practice: physicians, surgeons, podiatrists, physiotherapists, occupational therapists working all together in order to provide the best treatment and quality of life to the patients. This really took me by surprise, because in Italy the management of patients is permitted to physicians and nurses only. I also improved and deepened my knowledge in the pathophysiology of PFPS and became familiar with the structure and operational system of LMBRU’s global vision as a large academic rheumatology department. Likewise, I learned about the rehabilitation programme and projects being developed in the department and discussed our own research plans. I also had the opportunity to meet PhD podiatry students involved in different studies on rheumatic diseases and had valuable discussions concerning their research, especially on movement analysis side.

This visit encouraged me to go on with the research and allowed me to get new ideas on how to combine different kind of diagnostic imaging technology to start a new project at my own facility. It will bring advances in the area of PFPS diagnosis and treatment in Italy. I would like to thank all the people I met at LMBRU for making my educational visit so interesting and Dr Anthony Redmond in particular for inviting me.

Hopefully, there collaboration with LMBRU will continue. I would also like to thank the EULAR HP Standing Committee for allocating the grant for my educational visit.

With kind regards
Lorenzo Cavazzuti
PT Bsc Assistant Researcher

Apply for a grant:

Educational visits for health professionals in rheumatology

EULAR awards up to 10 bursaries for educational visits to health professionals other than physicians working in the field of rheumatology. The objective is to improve the standard of research and care in allied health professions and to foster collaboration across clinical units in Europe. Bursaries will not be granted to applicants who are already abroad in a visiting programme.

The amount of each bursary is between EUR 750 and 1,500 (the annual total amount granted is EUR 7,500).

Applications should be submitted by e-mail to the EULAR Secretariat at gabriela.kluge@eular.org.

Recipients are required to submit a report (maximum 1 page) to the EULAR Secretariat after the stay, focusing on the results that have been achieved.

Application guideline available at: http://www.eular.org/health_professionals_educational_visits.cfm
I had the pleasure of receiving an educational visit grant to the Orthopaedic Unit of the Leiden University Medical Center LUMC to learn more about implementation science. Dr Thea Vliet Vlieland hosted me for a week together with Dr Leti van Bodegom-Vos, post-doc implementation fellow of the Unit of Clinical Decision Making at LUMC. Implementation is a discipline already quite established in the Netherlands, but not in Switzerland. Implementation research focuses on the planned and systematic approach to introduce and evaluate innovations in clinical practice. I consider this discipline highly relevant as it fosters transfer from research to clinical practice.

Educational visit to the Netherlands
Exploring implementation science at Leiden University Medical Center LUMC.

A protocol for the implementation
The aim of the visit was to learn to develop a protocol for the implementation of cardiovascular training (CVT) in the Bechterew exercise groups. Our own trial, conducted in close collaboration with the patient organisation (Swiss Ankylosing Spondylitis Association SVMB) has demonstrated that CVT is effective and safe for Bechterew patients. The patient organisation organises the Bechterew exercise groups in Switzerland and now aims to add CVT to their exercise groups. My job will be to develop and guide this implementation process.

The visit was scheduled for 5 days and the hosts had organised a very interesting and helpful programme. It was a great mixture between introducing me to different topics related to an implementation process and research, discussing ideas and problems related to my own implementation topic and time slots to develop and write the protocol. Discussions on the first day covered the first steps of starting an implementation process, e.g. analysing current practice, content and feasibility of the innovation, noting possible barriers and facilitators and identifying target groups.

‘The story behind’
The second day was dedicated to qualitative research methods, e.g. conducting focus groups or interviews. Different researchers presented their projects and also talked about ‘the story behind’: problems, barriers and challenges that occur in any project but from such experiences one can learn the most. On the third day, we discussed more in-depth the elements to be implemented in my project and the plan to address the different target groups. Another issue was the way and methods to quantify and rank the barriers and facilitators that were identified.

The 4th and 5th day were used for discussing appropriate outcomes and outcome measures in an implementation project and how to set up my project to best cover the scientific issues as well as the practical interests of a patient organisation. An example of a project about Shared Decision Making illustrated that different health care providers as well as the patients may have their own preferences, which may challenge an implementation process. In addition to the scientific inputs and discussions, I was given insight into some interesting practical issues and facilities. One evening, I had the pleasure to participate in a Bechterew exercise group and discuss with the participants and the group leader Ria de Jong. I could also visit the Reade Rheumatology Rehabilitation in Amsterdam and discussed with my PT colleagues Wilfred Peters and Salima van Weely. At the multidisciplinary day care ward, at the LUMC, I was hosted by the Sole Mio. The head nurse Liesbeth Beaart-van de Voorde took time to explain the interesting concept and I also had the opportunity to discuss with nurses, physiotherapists and occupational therapists.

I would like to thank very much all the people for discussing their projects in an open and constructive way. The project has just started; we will stay in contact and collaborate!

Dr Karin Niedermann
Zurich University of Applied Sciences, School of Health Professions, Institute of Physiotherapy, Winterthur, CH

Dr Karin Niedermann is the president of health professionals in rheumatology Switzerland (hpr).
A huge thank you to everyone who has shown their support for people with rheumatic and musculoskeletal diseases (RMDs) on Waving for World Arthritis Day. We are thrilled that more than 63,000 people from over 80 countries around the world took part in our campaign!

The Waving for World Arthritis Day campaign has now ended, but you can still view the fabulous gallery of photographs and videos at http://www.worldarthritisday.org/.

The EULAR health professionals research grant

Every year EULAR funds one health professional's research project in the field of arthritis/rheumatism that is in line with the mission, objectives and goals of EULAR. Projects will be funded up to a maximum of EUR 30,000.

Recipients of a research grant must submit a mid-term report to the Scientific Committee of the EULAR Health Professionals on the progress of the research project.

After completion of the project the recipients must report to the EULAR Executive Committee on the results achieved. Furthermore, the recipients are expected to present their project in the EULAR HP newsletter and may be invited to present their findings at the annual EULAR congress.

**Application process**

Applicants must complete the official application form (including detailed budget), and include the full CV of the project leader as well as a project plan. For further instructions see the official application form.

Applications for 2014 should be e-mailed to Ms. Patrizia Jud at the EULAR Secretariat (patrizia.jud@eular.org) to arrive no later than 13 November 2013.

Applications will be evaluated by the Scientific Committee of the EULAR Health Professionals. Applicants will be informed by e-mail.

More about the application form and evaluation criteria at:
http://www.eular.org/health_professionals_research_grants.cfm

Read previous issues of EULAR HP News

EULAR HP News are available at
http://www.eular.org/st_com_health_professionals.cfm

Enjoy!

Do you have good news for the newsletter?

Since 2000, the HP Newsletter has functioned as the main information channel of health professionals in rheumatology within EULAR. The newsletter is published twice a year featuring the work of health professionals and all aspects of multidisciplinary collaboration.

Please give us tips about health professional thesis, projects, and new research themes in the musculoskeletal field. Contact the editor of newsletter for further information: jaana.hirvonen@reumaliitto.fi.

Rheumatology is interdisciplinary teamwork

Health professional (HP) collaboration is essential in the care of a person with rheumatic or musculoskeletal disease (RMD).

A team specialised e.g. in rehabilitation can include health professionals such as:

- rheumatologist
- nurse
- occupational therapist
- physiotherapist
- psychologist
- social worker
- nutritionist
- podiatrist
- free-time instructor
- and other health professionals

The person with RMD is in focus.
Get ready for the next congress:

**EULAR 2013 Madrid, Spain 12-15 June 2013**

**Abstract submission**

The electronic abstract submission system will be open until the 31 January 2013.

Abstracts received after the deadline will not be accepted. Health professionals (HP) can choose to submit their abstract either for practice and clinical care (HP topics A5) or for clinical research work (topics 11-34).

Please note that when submitting to topics 11-34, you work will be scored by rheumatologists, whereas the HP topics A1-A5 are scored by health professionals.

The full programme is available at EULAR website: www.eular.org.