

eular

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HP news

Newsletter of the Health Professionals in Rheumatology



From the Editor: Right to personalised treatment.....	2
Interviewing the Chair-elect Thea Vliet Vlieland.....	4
Recommendations on non-pharmacological management of hip and knee osteoarthritis	6
Welcome to London!	7
Jackie Hill: Health professional past and future in EULAR	12
Sex and sexuality for people with arthritis	14
Experiences from implementation of an evidence-based intervention in rehabilitation	18

Right to personalised treatment

The world is full of local, regional or global theme days, weeks and months. The goal of many such theme events is to raise awareness about important issues or to raise funds for good causes. As people working in the field of musculoskeletal conditions ought to know, World Arthritis Day takes place annually on 12 October. Perhaps fewer know that World Lupus Day takes place on 10 May. And two days from that, on 12 May, it is time for Fibromyalgia Awareness Day. Several other musculoskeletal conditions have their own theme days, too.

Theme day for patients' rights

This spring I heard the first time about an important theme day bringing together different diagnosis groups for a common cause. On 18 April the Active Citizenship Network organised the fifth European Patients' Rights Day. The network consists of 100 civic organisations from 30 countries. The network has defined 14 basic citizens' rights related to health care services.

The goal of the day is to highlight, discuss, and act for the improvement of patients' rights throughout Europe, as there are still big differences in the European health care systems and in the health of Europeans. The difference in the life expectancy of men, for example, may be as much as 20 years (10 years for women).

Report on the state of patients' rights

This year the theme day was celebrated more festively than usual. In honour of the day, a report, based on an audit conducted by the network in 21 countries, was published about the experienced state of patients' rights in the health care system. Civic organisations of the countries participating in the survey audited the state of patients' rights in hospitals. The rights situation was best with regards to physical access, i.e. signage to hospitals was good, hospitals were accessible by public transport, and patients could move in them in spite of mobility limitations. The situation

was rather good also in rights to privacy and confidentiality, the right to preventive measurements and the right to personalised treatment. However, none of these rights were fully respected in the countries participating in the survey. The situation was worst for the right to respect patients' time, the right to free choice and the right to access to care. To simplify a bit, it might be said that a patient can enter the hospital easily, but there is still a lot to do when it comes to patients' possibilities to make real choices and participate in making care decisions together with the professionals.

A new directive will enter into force late in 2013

Is there an added value resulting from a survey like this? First, it has created new practical, innovative methods, involving citizens and civic organisations, of collecting and analysing information. Moreover, the action has enabled the collection of important comparative information e.g. from the whole EU area for developing health care services, and at the same time the results provide information about the actual situation of patients' rights in different countries. Obtaining comprehensive information about the situation of different countries is important for many reasons. Late in February, for example, the EU Directive on cross-border health care entered



into force. According to the directive, patients from the EU countries must receive treatment equal to that of native citizens. An EU citizen must be compensated for his/her treatment in another member state, if corresponding treatment falls under compensable care in his/her own country. The regulation of the Directive will be binding by the end of 2013, which means that within a relatively short period national legislation and social security systems must be adjusted to enable the rights provided by the Directive, let alone harmonising the varying national systems.

Projects like this survey provide important information about the challenges faced in the patients' rights situation on the European level, enabling joint action to be taken to improve the rights.

By the way, do you know why 25 May will be an important day? It is the first day of EULAR congress held in London this year. I hope we will meet there.

Jaana Hirvonen

Editor

14 basic citizens' rights related to health care services

- | | |
|---|---|
| 1. Right to preventive measures | 8. Right to the observance of quality standards |
| 2. Right of access | 9. Right to safety |
| 3. Right to information | 10. Right to innovation |
| 4. Right to consent | 11. Right to avoid pain |
| 5. Right to free choice | 12. Right to personalised treatment |
| 6. Right to privacy and confidentiality | 13. Right to complain |
| 7. Right to respect of patients' time | 14. Right to compensation |

Rights by Active Citizenship Network

The complete rights are available at:
<http://www.activecitizenship.net/images/stories/media/EuropeanDay/manifestocartaing.pdf>

Cost- and time-effective interdisciplinary health care



Hi Tanja,
you forgot to place a splint on this one.



Illustrator Satu Cozens is the new caricaturist of the EULAR HP Newsletter. In her drawings, she will focus on the wonders of health professional work.

Picture source: John Cozens

eular HP news

Newsletter of the Health Professionals in Rheumatology

Editorial office

Publisher EULAR Standing Committee of Health Professionals in Rheumatology
www.eular.org/st_com_health_professionals.cfm
 Editor Jaana Hirvonen, jaana.hirvonen@reumaliitto.fi
 Editorial assistant Mikko Väisänen, mikko.vaisanen@reumaliitto.fi
 Layout design Heikki Luukkonen, HL-Mark, Finland

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Seestrasse 240
 CH-8802 Kilchberg
 Switzerland

On the cover: Rehabilitation is about teamwork. Patient's role as the key expert of his/her own treatment is self-evident. Picture is from the Rehabilitation Institute Apila, which is owned by the Finnish Rheumatism Association.

All pictures used in the newsletter by Mikko Väisänen if not indicated otherwise.

In this issue

This EULAR HP Newsletter is a specially printed Congress edition ready for London. The Local organizers of the HP booth this year are the British Health Professionals in Rheumatology (BHPR). Read more of the HP Congress activities and scientific programme from this issue. Likewise, we introduce the updated EULAR HP member campaign material now available for national HP associations.

Along with other interesting themes, we have an interview with our Chair-elect of the HP Committee, **Thea Vliet Vlieland**, who tells about her views on health professionals EULAR future and the further need for multidisciplinary research as well as the latest on the recommendations on non-pharmacological management of hip and knee osteoarthritis.

Dr. **Jackie Hill** is retiring after many EULAR-filled years. In her farewell contribution, she recollects the health professional highlights and advancements. PARE board member **Codruta Filip** from Romania wrote us an awesome article on people with RA and sexuality based on her own experience. Occupational therapist, PhD-student **Ricardo Moreno Rodríguez** explores the same theme from a professional perspective in Spain, and finally Physiotherapist, PhD **Florus van der Giesen** gives an overview on the experiences from implementation of an evidence-based intervention in rehabilitation

.... to mention only a few themes of this issue.

Nine questions for the chair-elect

Dr. Thea P.M. Vliet Vlieland is the chair-elect of the EULAR Standing Committee of Health Professionals in Rheumatology. She works as an associate professor at the Leiden University Medical Center in the Netherlands. In the following interview, the new chair unveils her thoughts on research, HP priorities, and HP Committee goals in EULAR.

Do you define yourself as a theoretical researcher or are you keener on the practical developments in the health care?

– I would say that I am a researcher on practical developments in health care.

Do you think that patient-centered care is already a self-evident goal in health care?

– Patient-centredness is indeed an important attribute of care, but it is insufficiently achieved in many cases. We have a strong tendency to design and deliver care from the providers' perspective. Therefore, this topic is still a challenge for patients, providers, researchers, and other stakeholders.

What are your main interests in the care of people with rheumatic diseases?

– The development, evaluation, and implementation of non-pharmacological interventions.

The Netherlands is often seen as a forerunner in the development of new health care approaches. What would you like to bring with you to EULAR as a typically "Dutch method"?

– Enthusiasm and energy. Practical experience as well as research experience in the field of arthritis care. We need a well-functioning network of clinicians and researchers in arthritis care meaning both health professionals and rheumatologists, closely collaborating with patients.

In your personal view, what are the main differences between inter- and multidisciplinary health care approaches?

– I find the distinction a little artificial, collaboration and communication among all team members (health care providers and the patient) needs to be optimised. How this is achieved depends on many factors, such as the goal of the treatments, health

care providers' level of knowledge and skills, preferences of the patient, opportunities and facilities to communicate and so on.

Some seem to think that there is not enough dialogue between physicians and other HPs. Do you find that this is the case?

– In EULAR, we have various possibilities to enhance the collaboration with physicians. Rheumatologists are involved in projects initiated and executed by HPs such as the development of HP recommendations and courses. Vice versa, HPs are invited to contribute to many EULAR activities initiated by physicians. It is important to make use of every opportunity to collaborate.

Where you like to see the HPs within 10 years' time?

– Over the past years, the HPs in EULAR have achieved a lot. For example, a structured organisation (having Vice-president, Standing Committee, and a Scientific Sub-committee); a growing number of member organisations;

a high-quality scientific programme during the annual EULAR congress; various international projects funded by HP grants from EULAR.

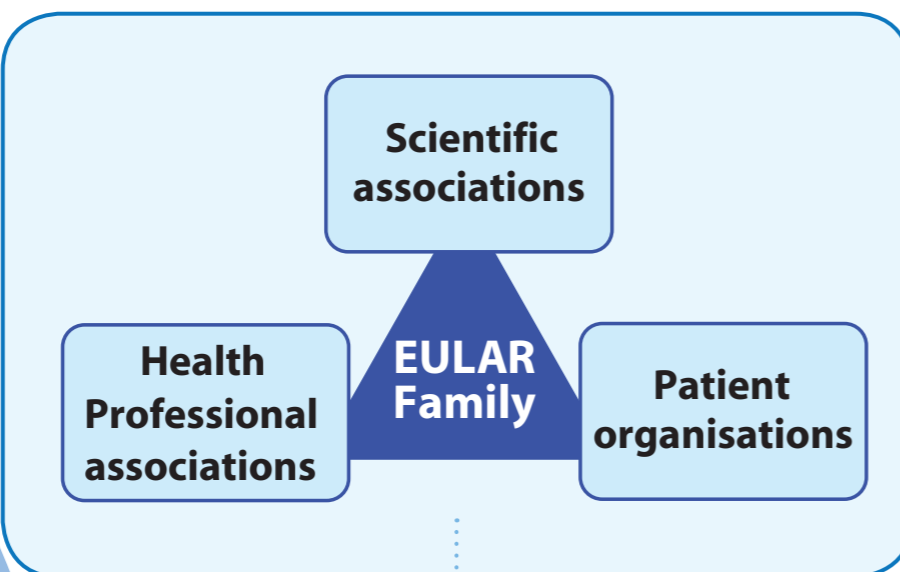
– In 10 years' time, I would like to see an even more professional and effective organisation, offering a core curriculum of education for HP in rheumatology as well as evidence-based recommendations, more new HP organisations in Europe, and thus more members of the HP Committee.

What are your goals as the new chairperson?

– I would like to build further on the work that has been accomplished by my predecessors. An important goal for the short-term is, in line with the strategic goals of the HPs, to establish a sub-committee for education.

Your term will be for the next 2 years, what would you like to accomplish in that time together with the HP Committee and the Vice-president?

– Increase educational activities for HP through EULAR, e.g. by means of more teach-the-teacher courses and an online course. Also further improve the HP programme during the EULAR Annual Congress, e.g. by providing more sessions, including workshops for clinicians. It is also vital to foster collaboration among researchers in HP care by means of encouraging joint, international projects. With all activities, it is very important to take the possible differences in approaches among member states into account and to work closely together with patients and rheumatologists.



The EULAR family



**Contact information:
Thea P.M. Vliet Vlieland**

MD, PT, MBA, PhD
Chair-elect of the EULAR Standing Committee of Health Professionals in Rheumatology
Associate Professor
Leiden University Medical Center
Department of Orthopaedics J11, PO Box 9600, 2300 RC
Leiden, the Netherlands
T.P.M.Vliet_Vlieland@lumc.nl

Dr. Thea P.M. Vliet Vlieland would like to enable a core curriculum of education for European health professionals in rheumatology.

“It is vital to foster collaboration among HP researchers by encouraging international projects.”

Thank you Tanja!

Dr. Tanja Stamm's term as the chair of the HP Committee is coming to an end. She has enjoyed working within EULAR for HPs. She will advise and assist Thea P.M. Vliet Vlieland with taking over the duties of the chair. Rewardingly, the status of HPs within EULAR has notably risen during the last decade which gives good ground for handling the responsibilities of a chair in a productive way.

According to the soon resigning Chair Tanja Stamm, ever-deepening cooperation with scientific associations (rheumatologist) and patient organisations (PARE) is essential for a prosperous HP future in EULAR.



Picture source: Petra Spiola

– To me within my time at EULAR, the most eye-opening thing was to learn in practice how much the health professionals had already achieved in EULAR over the years – and what we still can achieve. Important, interesting and fruitful but also sometimes demanding in a constructive sense was the cooperation with the rheumatologists and the people with rheumatic diseases, Stamm says.

Tanja Stamm foresees Thea P.M. Vliet Vlieland as a splendid chair.

– Thea can be a very good link between the physicians and health professionals as she is both in one person. I think that Thea is an excellent researcher and clinician but also a very diplomatic person and this combination may be very powerful for the Health Professionals in EULAR. I wish Thea all the best for the coming two years, Stamm sums up.

Recommendations on non-pharmacological management of hip and knee osteoarthritis

The current recommendations on the management of hip and knee osteoarthritis put much emphasis on non-pharmacological management, but are not sufficiently specific about the content, timing, intensity, frequency, duration, and mode of delivery of this non-pharmacological management. The HP Committee has started a new project in order to identify these evidence gaps.



Picture source: NIOR

Norwegian PhD Linda Fernandes is the research fellow of the recommendations on the management of hip and knee osteoarthritis project.

Our aim as health professionals is to develop evidence and expert opinion-based EULAR recommendations for non-pharmacological management of osteoarthritis of the hip and knee and determine a future research agenda, tells Thea Vliet Vlieland, one of the convener of the project together with JW Bijlsma and Kåre Birger Hagen.

The target population for this project includes rheumatology health professionals from various professional backgrounds, rheumatologists, orthopaedic surgeons, general practitioners, and people with osteoarthritis of the hip and/or knee, as well as researchers working in the field of osteoarthritis management, health insurers, and health policy makers.

Physiotherapist, PhD **Linda Fernandes** will operate as the research fellow of the project. She has recently defended her thesis on functioning, disability, and management of patients with hip osteoarthritis.

How to proceed

The Steering Group preparing the development of the recommendations determines a maximum of 10 propositions for non-pharmacological management of hip and knee osteoarthritis through a Delphi procedure. A systematic literature search on the selected topics will then be conducted, using for instance the Cochrane library and Medline and other databases.

The plan is to carry out a methodological evaluation concentrating on studies on effectiveness of relevant interventions. All evidence will be reviewed and expert opinion will be documented to find out where the evidence is insufficient or absent. We hope that results of this project will contribute to the quality of care for people with hip and knee osteoarthritis across Europe, Thea says.

The HP Vice-president Kåre Birger Hagen, the chair of the HP Committee Tanja Stamm and chair-elect Thea Vliet Vlieland feel privileged to welcome all health professional to the EULAR Congress in London.



The Local organizers of the HP booth this year are the British Health Professionals in Rheumatology (BHPR) and we are very grateful to Diana Finney and Lindsey Hawley - BHPR Past President and President - for arranging everything.

Welcome to London! Drop in for a cup of tea

The British Health Professionals in Rheumatology hope to see lots of colleagues in London.



Picture source: BHP

The EULAR Congress in London provides an exclusive opportunity for European health professionals, researchers, and colleagues to interact.

Both as a member of the Local Organising Committee and the BHPR, it is an honour for us to invite you all to the HP booth at the EULAR Congress, says Diana Finney.

Find us at the HP booth

The health professional booth is located in the EULAR Village at stand no V1-V2-V3. As in the previous congresses, the village interlinks all EULAR social activities in the same location and creates a favourable atmosphere for informal meetings. Most of the EULAR-related activities and sister societies will be displayed in the village. National health professional member organisations of EULAR present their activities at the booth.

All HPs can pop in for a cup of tea or coffee at the booth, that is the recommended British way to have a break, **Lindsey Hawley** suggests warmly.

HP information

At the booth, new national representatives from Europe can learn more about the ongoing HP member campaign, get information on how to become a member, update their knowledge on EULAR and the HP Committee work, and leave their contact information for further details.

Wii Station

This year we have arranged to have a Wii station at our HP stand, where everyone can test their balance on a Wii board. Physiotherapists in Great Britain have been using this as method of rehabilitation of patients with arthritis affecting their feet. We

hope to run a competition to see who gets the highest score so do come along and have a go.

HP networking meetings

Also this year there are Networking Meetings for the different HPs in rheumatology which coincide with the Scientific HP programme of the Congress. Below is the timetable for the Networking meetings, please take advantage of these. You do not need to register in advance and they are a good opportunity to network with HPs with similar interests.

The preliminary health professional networking programme and activities at the HP booth

Wednesday	Thursday	Friday	Saturday
	08:00–09:00 Health Professionals Scientific Sub-committee, Room S05	08:00–09:00 Psychologists Meeting, Room S05	Please notice also the HP Scientific programme and the HP poster presentations
12:00–17:00 the HP booth is open: welcome to the Wii station at stand no V1-V2-V3		08:00–09:00 Physical Therapists Meeting, Room S06	
13:00–14:30 Health Professionals Standing Committee Meeting, Room S05		09:00–10:00 Social Workers Meeting, Room S05	Highlights of the Congress
16:30–17:00 Informal get-together at the booth hosted by BHPR		09:00–10:00 Occupational Therapists Meeting, Room S06	See you next year in Berlin!
		17:00–18:00 Nurses Meeting, Room S14	



Paris 2008



Copenhagen 2009



Rome 2010

The HPs have had their own stand at the EULAR Congress since 2008 in Paris. The booth works as meeting point for all HPs and a place to network and share ideas.

Join in!

The EULAR Member Campaign for Health Professional Associations in Europe

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.

In spring 2011, EULAR had seven health professionals associations as members:

- the British Health Professionals in Rheumatology (BHPR)
- the health professionals in rheumatology Switzerland (hpr)
- the Netherlands Health Professionals in Rheumatology (NHPR)
- the Swedish Rheumatology Forum (SveReFo)
- the Norwegian Interdisciplinary Organisation in Rheumatology (NIOR)
- the Danish Interdisciplinary Forum (DIRF)
- the Serbian Association of Health Professionals in Rheumatology (SAHPR)

Each member organisation can delegate a representative to work on the EULAR Standing Committee of Health Professionals in Rheumatology. In addition, the committee also includes interested professionals from other European countries who are planning to establish a national HP organisation that could subsequently apply for EULAR membership. Do not hesitate to ask for further information on this process.



The EULAR Standing Committee of Health Professionals in Rheumatology had a very productive meeting in ROME.

Delegates from EULAR member organisations in the Committee of HPs in Rheumatology

Denmark, the Netherlands, Norway, Serbia, Sweden, Switzerland, the United Kingdom

Co-opted countries:

Austria, Czech Republic, Cyprus, Estonia, Finland, Germany, Italy, Lithuania, Poland, Slovakia, Slovenia and Spain.

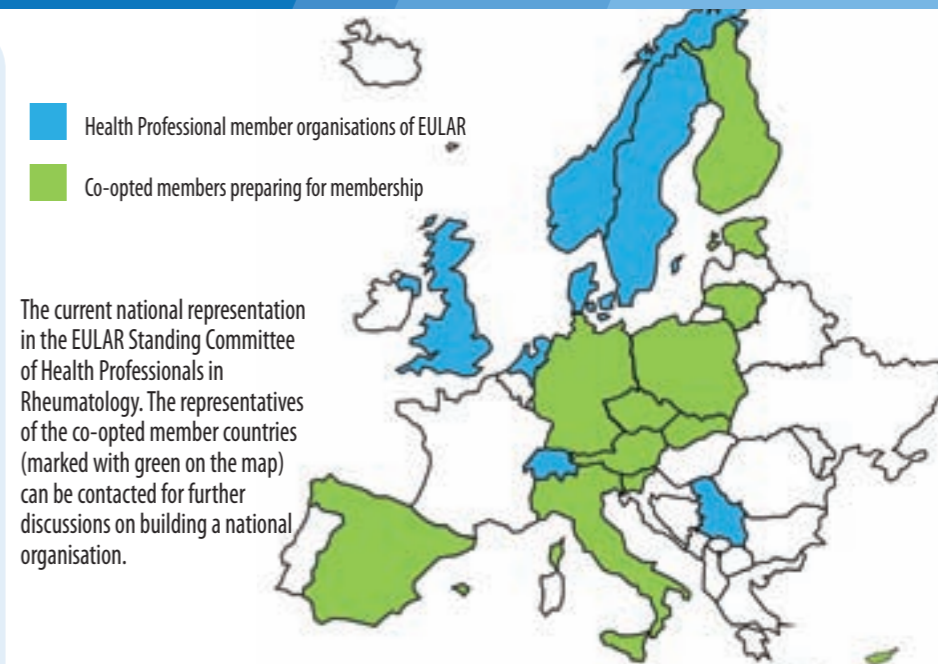
EULAR Standing Committee of Health Professionals in Rheumatology endorses multidisciplinary collaboration in the treatment of rheumatic and musculoskeletal diseases in Europe. The Committee was established in 1989 as a European platform for cooperation and shared information

among the different health professionals working with rheumatology. The Committee encourages health professional research in rheumatic and musculoskeletal diseases and works also to improve the patient's role as the key expert of his/her own treatment.

As a EULAR member organisation you can:

- interact with colleagues on European and international levels
- retrieve first-hand information on the latest recommendations in the state-of-the-art care and treatment of rheumatic and musculoskeletal diseases
- contribute and participate in the development of health professional research
- organise and participate in health professional educational courses
- promote your national HP association's work at the yearly EULAR congresses (networking meetings, HP booth etc.)
- have an easy-access to the information on EULAR's facilities for health professionals such as educational visit grants and research grants
- and most of all: be part of a European health professional network with direct connections to other national HP organisations'

WELCOME!



The current national representation in the EULAR Standing Committee of Health Professionals in Rheumatology. The representatives of the co-opted member countries (marked with green on the map) can be contacted for further discussions on building a national organisation.

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 co-opted representative in the Standing Committee of HPs. If so, please contact this person regarding your involvement in EULAR. You will find the member list of the Committee at www.eular.org/st_com_health_professionals.cfm.

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.

HP member campaign flyer available at: www.eular.org/st_com_health_professionals.cfm

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 a 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 co-opted member in the EULAR Standing Committee of HPs. As a co-opted member 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. Tanja Stamm: tanja.stamm@meduniwien.ac.at.



Nursing Science Summer School at Witten-Herdecke University, Germany

Advanced Nurse Practitioner in Rheumatology Patricia Minnock from Our Lady's Hospice and Day Services, and a PhD clinical research fellow at the School of Nursing and Midwifery, Trinity College Dublin received a EULAR grant to participate in the European Academy for Nursing Science (EANS) summer school. The methodology school was especially organised for nurses undertaking PhDs.



Patricia Minnock is a PhD clinical research fellow at the School of Nursing and Midwifery in Trinity College Dublin, Ireland.

– This was an excellent and most enjoyable opportunity. The international collegiality is not to be underestimated. In plain English, it is fun to work with, and establish a network of friends and colleagues across Europe, Minnock says.

A 3-year programme

The Academy links individual nurse scientists from University Departments of Nursing in which there are active doctoral programmes. It provides a forum for nurse researchers to meet and develop a European perspective to their work.

– New students commence the course each year, starting in year 1 and progress through the programme. On completion of the 3-year programme, participants are awarded, over and above their degree from their own university, a Certificate which details the European dimension of their work and is recognised by the European Academy of Nursing Science, Minnock explains.

She completed the first year's 2 week programme in 2009 at Turku University, Finland which was funded by the European Union's Framework 6 Marie Curie Scheme.

– My second year's one week programme at Witten-Herdecke University, Germany, was covered by the EULAR HP educational visit grant. Next year's school takes place in Lund University, Sweden, for 1 week in July, tells Minnock.

Nursing as research and practice

The EANS 2010 summer school implemented a new curriculum to ensure that mixed research methods will become a norm in nursing research exploring the whole complexity of the profession.

References

MRC (2000) A Framework for Development and Evaluation of Rcts for Complex Interventions to Improve Health. Retrieved from <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC003372> on August 23rd 2010
 MRC (2008) A Framework for Development and Evaluation of Rcts for Complex Interventions to Improve Health. Retrieved from <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC004871> on August 23rd 2010

– Nursing is a complex intervention containing a number of component parts with the potential for interactions between them which, when applied to the intended target population, produce a range of possible and variable outcomes. This is the reason why developing an evidence base is a considerable challenge, says Minnock.

The Nursing Science curriculum was based on the Medical Research Councils' (MRC 2000, 2008) framework for investigating complexity in health care delivery through an integrated process of development, feasibility, piloting, evaluation, and implementation, where there is a non-linear and dynamic interchange between stages.

– The EANS programme aims to equip the next generation of nurse researchers with the methodological experience and expertise, knowledge, skills, infrastructure, and finance to undertake research which is programmatic, multidisciplinary, theory-based, and integrated, Minnock continues.

The overarching aim of this curriculum is to ensure that the complex nature of nursing will be recognised explicitly in research programmes and that these respective programmes will become increasingly multi-state, -disciplinary, and -programmatic in order to develop knowledge for practice that can be translated into everyday health professional use.

Patricia Minnock highly recommends the programme to all doctoral nursing students.

More information is available at: <http://www.european-academy-of-nursing-science.com/>

Example of an educational visit report:

Visiting the Leeds Institute of Molecular Medicine

Rheumatology nursing has been evolving over many years in countries like the United Kingdom and Netherlands, however in Portugal this area just started to emerge.

Regarding this development, as a Portuguese nurse working within a multidisciplinary team in the rheumatology research area, this contact with one of the best Rheumatology centres of Europe was a unique opportunity. I was at the Leeds Institute of Molecular Medicine and the Academic & Clinical Unit for Musculoskeletal Nursing for one month. For this trip, I had received financial support from EULAR.

Team in action

During this visit, I had the opportunity to witness an excellent multidisciplinary team work: doctors, nurses, podiatrist, physiotherapists, occupational health professionals, and psychologists working all together in order to provide the best treatment and guarantee the best quality of life to the patients.

I also had the opportunity to develop my knowledge in rheumatology nursing, acquire a global vision of the structure and operational system of Leeds Institute of Molecular Medicine and observe specialist nurses to perform the following functions: patient education, anti-rheumatic drugs handling and administration during patients' consultation and emotional support provided. I also

familiarised myself with research projects being developed in the department at the time.

New ideas and scientific parameters

Rheumatic diseases are chronic conditions the nature of which requires that patients have different types and times of nursing intervention. The nursing intervention can vary from the very essentials of nursing care such as help with the activities of daily living, pain management, maintaining tissue viability, and patient education to highly technical activities such as intra-articular injections and administration of intravenous infusions.

This visit allowed me to get new ideas and scientific parameters to start a new project in the rheumatology department at Coimbra's University Hospital and will also bring huge advances in the area of rheumatology nursing in Portugal.

With kind regards

Andréa Ascensão Marques

Nurse in the Rheumatology Department of Coimbra University Hospital



Education Programme Coordinator Gabriela Kluge is happy to help out with applications for an educational visit.

Apply for a health professional educational visit 2011

EULAR awards up to 10 bursaries for educational visits to health professionals other than physicians working in the field of rheumatology to enable them to visit colleagues in another EULAR member country. The amount of each bursary 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. In 2010, EULAR received six applications for a health professional visit. The HP Committee encourages health professionals to use this great opportunity to widen horizons in the professional sense.

How to apply?

The next application deadline is 31 March 2012. Applications should be submitted by e-mail to the EULAR Secretariat at gabriela.kluge@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. Recipients are required to submit a one-page overview as a report to the EULAR Secretariat after the visit, focusing on the results that have been achieved.

The application form and the contract to be signed with terms and conditions are available at: www.eular.org/health_professionals_educational_visits.cfm



Picture source: John Verhoeff

EULAR as a unique forum for HPs

Thirty years ago, I became a member of the Rheumatology and Rehabilitation Research Unit of the University of Leeds (RRRU), and although at that time I was a very experienced senior nurse, I knew very little about rheumatology.

My first love had been general surgery, where people came into the ward very ill and usually left cured; how very different from what I was about to experience. I joined the RRRU, not through an interest in Rheumatology, but because I wanted to gain experience in research. Little did I know that this move would change my working life forever!

It did not take me long to realise that nurses and health professionals (HP) in general could make a real difference in the patients' experience of living with their disease and that we could play a much bigger part in their care in clinics than was the normal practice at that time. However, if we were to make a real difference, we needed to disseminate our experiences and our research results much more widely.

I attended my first EULAR conference in 1987 and gave a paper "The effect of a request card on the type of container used to dispense drugs to patients with rheumatic disease". It was at this meeting that I realised the importance of EULAR as a unique forum for exchanging ideas and experiences with nurses and HPs from other countries and I have attended almost every conference since. In those early years, the numbers of delegates at EULAR conferences were small compared to the many thousands

who attend now and conferences were only held every four years. Many changes have taken place in the organisation since those early days. At that time, the HPs' Vice-president had to organise the whole of the HP section of the conference single-handedly, an enormous task. Subsequently, under the leadership of consecutive HP Vice-presidents, the number of HP representatives on the EULAR Scientific Programme Committee, the body which organises the yearly conference, has increased. I believe that this, combined with the call for session proposals, has made a significant difference to the quality and relevance of the conference to HP delegates.

Catalyst for new ideas

There remains, of course, the thorny problem of the small number of sessions available for HPs. Unfortunately, this is a "number of bums on seats" problem! It is hard to make the case that we need more sessions for HPs when they comprise just a few hundred delegates compared to many thousands of doctors and scientists. More recent changes include the creation of a Scientific Sub-committee, specifically for HPs, which meets at each EULAR conference to discuss the composition of the next conference. As well as assessing grant applications and the quality of conference

abstracts, this committee has also been an important catalyst for new ideas, concerning research projects and education programmes.

“ Our inclusion could have a big impact within EULAR and subsequently on EU practice. ”

Two recent EULAR-funded initiatives have highlighted educational needs. Firstly, the EULAR web-based survey of the current status of extended roles, taken by HPs within Europe, showed how the state of educational programmes varied from country to country. Secondly, the Task Force established to produce guidelines for the basic and advanced role of the nurse in the management of chronic inflammatory arthritis has identified a lack of educational consistency across the EU. Whilst some countries such as the UK are well catered for educationally, in others there is little or no rheumatology education apart from in-house teaching. EULAR has a major role in the provision of HP education. In addition, EULAR is well-placed to provide on-line programmes for HPs. These would be time consuming and expensive to develop but in the long run, such courses could make a major difference to the way in which care is provided and to the quality of patient care.

Unrecognised efforts and need for transparency

As I reflect on the changes that have occurred within EULAR over the past 25 years, I

realise how much HPs have progressed, particularly in the last decade. However, I also realise that the valuable work undertaken the EULAR HP Committees often remains unseen and unrecognised. This invisibility even occurs within the EULAR organisation itself. This is partly because HPs are very under-represented on relevant EULAR Standing Committees, such as Education and Training, Clinical Affairs, Investigative Rheumatology, and Epidemiology and Health care services. Our inclusion could have a big impact within EULAR and subsequently on EU practice. There is also a problem in that there is a lack of transparency regarding the way that EULAR functions. For instance, a number of colleagues have asked me how the HP Scientific Sub-committee is chosen or how they can become members or who chooses the HP Vice-president? These are valid questions and there are no secrets but there still appears to be widespread ignorance of these matters and this information needs to be broadcast as widely as possible, perhaps on the EULAR website.

Working as a team

As I approach my final EULAR conference before retirement, what of the future? I believe that EULAR will continue to flourish and to improve the lot of patients

Jackie Hill is retiring from EULAR after decades of work.



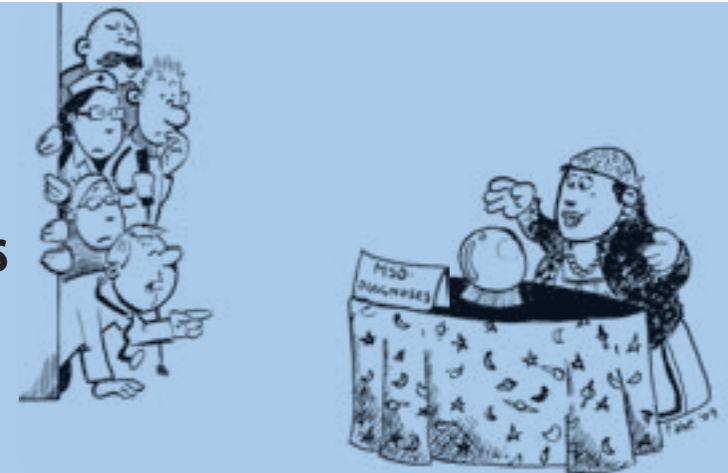
Jackie Hill

Is one of the first rheumatology nurses in the UK, PhD in 2000, Fellowship of the Royal College of Nursing, co-convenor of the EULAR Nursing Task Force to produce Recommendations / Points to Consider for the Basic and Advanced Role of the Nurse in the Management of Chronic Inflammatory Arthritis.

by enabling HPs within Europe to develop their knowledge and skills and to share information. However, if there is one thing that I have learned over the years it is that this can only be achieved by working as a team with our rheumatology colleagues and with patients and by appreciating and encouraging their input.

Much still remains to be done but with so many knowledgeable and willing HPs, rheumatologists and patients within Europe, I have no doubt whatever that EULAR will be the "must attend" conference for HPs.

Web-survey: The first data on extended roles of non-physician health professionals and innovative models of care within Europe



Due to the increasing prevalence of rheumatic diseases, extended roles of non-physician health professionals and innovative models of care may be important options in rheumatology in the future. Extended roles have been pioneered in the UK, Canada, USA and Australia and been found to be effective and safe. However, few data are available about mainland Europe, so the aim of this study was to explore the current status of the extended roles undertaken by health professionals within Europe, and the corresponding models of care used.

The used method

Non-physician health professionals from various European countries were asked to complete a web-based survey using convenience and snowball sampling techniques. Data analysis involved calculating descriptive statistics and frequencies based on the countries where the participants currently worked.

What was learnt

Of the 479 health professionals who filled in the survey, 430 (92%) indicated that they were performing extended roles. Considerable differences between the 27 participating countries existed, in terms of

which extended roles and which innovative models of care were being used. Barriers to performing extended roles were cited as the attitude of rheumatologists in all but eight countries, while attitudes of patients were less common barriers. Lack of knowledge, education and educational opportunities were also experienced in several countries.

We recommend increasing educational opportunities, as well as developing strategies to limit the barriers experienced.

Read more at Musculoskeletal Care 2011 Published online in Wiley Online Library (wileyonlinelibrary.com)

Health care:

Sex and sexuality for people with arthritis – a taboo subject or not?

What does a taboo subject mean? Taboo for whom? For the society? But I don't have sex with the society! I just have to live in the society. I am free to behave and do everything I can so that I and my partner are happy and strong as a couple. And sex is a very important part in this equation.

The keys to resurrecting a lagging love life are communication, planning, and a positive attitude. Communicating openly and directly with your partner, doctors and other health professionals (HP) is not always easy. People can have trouble discussing sexual issues since they can assume that they are expected to simply feel lucky to be able to manage in their daily lives and should therefore not have the need or even the right to “complain” about changes in sexual functioning.

How to approach a health professional?

What would be the first logical step, if one has the courage to ask guidance in these issues? Of course, talk to your rheumatologist, or other HP involved in your treatment, because s/he is the specialist you are seeing for your rheumatic condition. S/he knows all about your medical history, all about your chronic pain, all about your joints, all about your mobility – the lack of it – and your chronic fatigue.

But does s/he know anything about your most secret anxieties? Does s/he know anything about your sexual difficulties and fears of rejection and incapacity since you got rheumatism? And should s/he or all your health care providers, a team full of people, know all this? Would they care about this? Could they be of any help in this field? So many questions...

First, consult your doctor

In the beginning, it was inconceivable for me to talk to my rheumatologist, or any other HP for that matter, except my gynaecologist about my sexual difficulties. But there are some functional problems associated with arthritis/rheumatism which are not gynaecologist's specialty. For instance as a result of arthritis of the hip joints, it may be painful to abduct (spread) the legs in the missionary position of intercourse. This



Codruta Filip

Romanian League against Rheumatism
Member of PARE board
codruta.filip@gmail.com

Codruta Filip thinks that downright communication is essential in health care. – In the past, the doctor typically took the lead and the patient followed. Today, a good patient-HP relationship is more of a partnership where the patient and health professionals work together to maintain the patient's condition. You need to feel that you can talk about anything with your care providers. Too many patients let a lot of problems go for too long, due to fear or embarrassment of discussing it. A trusting relationship can make HP appointments worth their while, Filip says.

Picture source: Codruta Filip

usually happens in rheumatoid arthritis, osteoarthritis, and ankylosing spondylitis. Arthritis of the knees can also interfere with intercourse, if one person is on his or her knees. Arthritis of the back, as in ankylosing spondylitis or psoriatic spondylitis, can also interfere with one's sex life.

Anyhow, talking to a rheumatologist seemed like a dead end at first. I was too ashamed and I couldn't know how my rheumatologist would react. Besides, my rheumatologist is a man. With a woman rheumatologist it would have been easier, I guess, but with a man... I mean, they say that women come from Venus and men come from Mars. So how would I travel a distance of millions of kilometres and be understood? For a beam of light it takes about 18 minutes and 40 seconds from Mars to Venus. Then it hit me: I happen to possess the most powerful transportation means possible, my thought, which can travel even faster than the beam of light.

I made up my mind and I decided to see my rheumatologist and talk about my sexuality and the aspects considering my rheumatic disease. When making the appointment I clearly specified that I need a bit more time than normally to discuss a personal matter. In my point of view, this was the most difficult step to make.

Once I started to talk I saw that all

my fears were in vain. My doctor was open-minded about this subject and very willing to discuss this with me. He even told me that he was surprised that I had not approached the subject of sex with him earlier. He did not consider the issue a taboo but a necessary one. At the end of the conversation, after he had succeeded to make me feel comfortable talking about everything, he said that he had wanted to approach me earlier about this, but was afraid of my reaction or was worried if I was ready for such a delicate conversation.

So he was human too, after all. My fears had had no basis. It turned out that my rheumatologist is one of those doctors who open their minds and hearts to the patients.

Talking to kineto-therapist

Later on, I also discussed with my kineto-therapist specialist, fortunately a woman. Having a fit muscular system is helpful in an active sex life as a person with arthritis – you can sustain your body more and with less pain and you can have a longer lasting intercourse. I found out useful things in the process of creating new, comfortable positions for intercourse with my partner.

I was surprised to hear that she had already advised many other people with rheumatism of different ages and backgrounds. What a success, I thought!

Be proactive

I realised that my case was a happy one. You do not know for sure how your rheumatologist or other HPs would react when you bring such a sensitive topic on the table.

Maybe my own “how to do” list below could help people with rheumatism as well as

HPs to learn from my experience.

Our attitude is everything. It is common knowledge that for instance arthritis can lead to sexual challenges that may require adjustment on the part of the individual with arthritis and her/his partner. It is essential to communicate openly; let us be proactive both ways!

How to bring up sexual issues with HPs

- **Encourage** your doctor to realise that we really need a multidisciplinary approach when talking about musculoskeletal diseases; we need HPs to work together for us. Different health professionals can be consulted: a rheumatologist, an orthopaedist, a kineto-therapist, a sexologist, a psychologist, a gynaecologist, a physiotherapist, an occupational therapist, a trained nurse to name only a few.
- **Bring it up yourself.** I believe that open communication is a necessity and it is the first step towards any solution. Talking with a trained specialist about sex or sexuality is important. Do not avoid the subject, even if you are embarrassed or uncomfortable. HPs are usually used to talking about all matters and will try to ease your possible discomfort.
- You can **start the conversation** by saying: “Is there a way we could deal with

my concerns about my sex life? Could we take some time today to discuss how my condition can affect my sex life?”

- It is good to have a clear agenda of the issues you want to discuss; **Write down your questions** before you actually meet. Having them in writing can help you to stay on top of your sexual health care.
- It may help if you **bring your partner** with you.
- **Ask about everything:** the effects of the illness or disability on sexual function, about what influence medications or surgery may have, how to improve the intercourse positions. Find out also what there is to know about the positions that are not recommended for instance for the people with joint replacements.
- **Keep the door open** for future discussions. Ask your doctor to refer you to another member of the multidisciplinary team who can help you further.

Patient involvement The first patient research partners ready for scientific projects

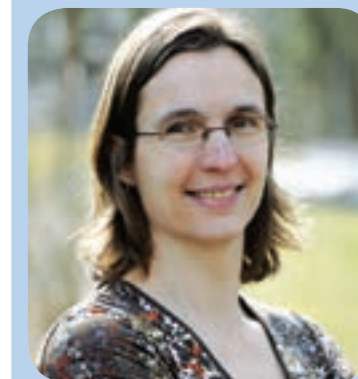
In spring 2010, the EULAR Standing Committee of PARE started a new project aiming at establishing a European Network of patient research partners. In May, sixteen people with a rheumatic condition were selected. In October, they participated in a two-day EULAR pilot training in Brussels, focusing on the value of experienced-based knowledge, methods of influencing research from a patient perspective and basic terminology, and concepts of qualitative and quantitative research. The training was given by rheumatologist Dr. **Laure Gossec** and convener of the project **Maarten de Wit**. The training was well-received and participants will now be nominated for new EULAR scientific projects.

Successful inclusion of the patient perspective

EULAR has eight recommendations for patient involvement in research projects. These recommendations provide practical guidance for organising patient participation, capturing (1) the role of patient research partners, (2) phase of involvement, (3) the recommended number, (4) recruitment, (5) selection, (6) support, (7) training and (8) acknowledgement.

Read more on recommendations at:

De Wit M.P.T., S.E. Berlo, G.J. Aanerud, et al. EULAR Recommendations for the inclusion of patient representatives in scientific projects, Ann Rheum Dis 2011;70:722-726



Picture Source: PARE

Project Coordinator Nele Caeyers, with Convener of the project Maarten de Wit, intends to develop a guide for principal investigators to facilitate the contribution of patient research partners in their projects.

More training to deal with sexuality and people with rheumatic diseases

Spanish occupational therapist's point of view

Occupational therapist, teacher, Coordinator of support program for students with disabilities, and PhD student **Ricardo Moreno Rodríguez** at University of Rey Juan Carlos, in Spain, finds it necessary to include professional approaches on how to address sexuality in the education of occupational therapists (OP). As all other functional themes, also sexuality should be automatically covered with patients with rheumatic diseases.

– OP is an advocate of self-care, activities of daily living, and occupational performance. S/he has to have the necessary skills to deal with sexuality; otherwise, we are losing a vital part in our profession and do not see the patient as a whole and with a holistic view, Moreno underlines.

According to a survey done in 2005, more than a half of OP students anticipated that they would not feel comfortable in dealing with sexual issues with their patients. Moreno sees that the attitudes may have slightly changed in five to six years.

– Initially, Spanish students say they would address the issue without problems, but the truth is that there is still trouble in managing sexual issues with patients and it is necessary to get more training in this area. I asked my OP graduate students and most of them felt able to face advising on sexuality in general but are not fully trained when it comes to the sexuality of people with disabilities. All of them agreed that the education received is limited in this sense and the curricula do not include specific matters about sexuality, Moreno says.

Next OP generation

It is likely that the future generations of Spanish OPs will be more accustomed with sexual matters connecting it to energy consumption, fatigue prevention, or joint protection. However, Moreno intends to cover part of the lack of education by discussing sexuality in OP classes.

– It is absolutely necessary to have a specific training on sexual dysfunction in order to be fully competent in this regard. This occupational area can affect the patients and generate a deep discomfort in them. OPs should be required – and be prepared to – successfully deal with sexuality, Moreno explains.

Treatment programs for people with fibromyalgia which I have been designing

until recently, included a specific intervention on sexuality and relationships. Actually in an intervention program, dealing with people with rheumatoid arthritis, sexuality is also one of the themes included that I have proposed as part of my doctoral thesis. Like any activity or occupation which has been lost or damaged, sexuality deserves our professional attention, Moreno hopes.

All team players involved

Ricardo Moreno Rodríguez has talked with other health professionals, primarily with psychologists and physiotherapists, about how to help out with sexual issues as an interdisciplinary team. He thinks it is easy to refer a patient with questions on sex to another HP.

– Specifically, the treatment of people with fibromyalgia is for us an interdisciplinary job between psychologists and occupational therapists, and if it was not a joint action we would not have achieved the results we expected. We have given seminars and workshops on sexuality and disability, aimed at students of occupational therapy, psychology, medicine, physiotherapy and nursing, with the intention of facilitating teamwork in this area, to deepen the knowledge they already have and eliminate false assumptions that there may be in many cases about sexual relations and people with disabilities, Moreno says.



A member of AEPROSER (Agrupación de profesionales de la salud en reumatología) Ricardo Moreno Rodríguez thinks Spain can be a little backward compared to northern Europe or the U.S., perhaps due to the fact that occupational therapy studies were only recently introduced in Spanish universities. – The curriculum changes should lead mainly to an improvement in this line for the training of occupational therapists, now that we are part of the European higher education area, Moreno says.

Rainbow families with rheumatic symptoms

Rheumatic and musculoskeletal diseases may strike all people regardless of their sexual orientation, gender identity and/or gender expression. ILGA-Europe is the European region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association. It emphasises the need to obtain and disseminate accurate information concerning the issues related to health of lesbian, gay, bisexual, trans and intersex (LGBTI) people. ILGA-Europe advocates equal access to health services and non-biased treatment for all people.

Health concerns of LGBTI people from the rheumatic diseases perspective:

- Access to services and to information
- Discrimination by health care providers
- Disclosure to health care providers
- Confidentiality
- Reproductive health
- Visitation rights of family members

Planning the EULAR Congress 2012

The next EULAR Annual European Congress of Rheumatology will take place between **6 and 9 of June 2012** in Berlin, Germany. The annual EULAR congresses which began in 2000 are now a major event in the calendar of world of rheumatology. The meeting will provide a unique occasion for the exchange of scientific and clinical information. It should facilitate interactions between patients, medical doctors, scientists and health professionals in Europe and from around the world.

Abstract submission for Berlin 2012

The electronic Health professional abstract submission system will be open until the **31 January 2012**. Abstracts received after the deadline will not be accepted. Health professionals can choose to submit their abstract either for practice and clinical care (topics A1 – A5) or for health professional research work (topics 7 – 27).

Health Professionals Travel Bursaries

Every year, EULAR awards a number of travel bursaries to the first or presenting author of a health professionals' abstract that has been accepted for oral or poster presentation at the EULAR Annual Congress.

A travel bursary shall facilitate attendance at the EULAR Congress and includes:

- free registration (including one year free subscription to the ARD)
- a cash amount of 350 EUR for travel and living expenses
- three nights hotel accommodation (single use), booked by EULAR

All health professionals other than physicians are eligible. There is no age limit for these bursaries.

The cash amount of the travel bursary will be paid in full on-site at the Congress only, and only to the eligible person. No prepayments will be made in any cases. Applications should be submitted via the electronic application system.

Further information at:

www.eular.org/edu_travel_bursaries_ahp.cfm.



Executive Assistant Patricia Jud will assist with all questions regarding the EULAR Health Professional research grant.

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.



Prescribe the newsletter free-of-charge at: www.eular.org/st_com_health_professionals.cfm.

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 € 30,000.

Recipients of a research grant must submit a mid-term report to the Scientific Sub-committee of the EULAR Health Professionals on the progress of the research project. After the completion of the project, the recipients must report the results to the EULAR Executive Committee. 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 available at: www.eular.org/health_professionals_research_grants.cfm.

Applications for 2012 should be e-mailed to Ms. **Patrizia Jud** at the EULAR Secretariat (patrizia.jud@eular.org) to arrive no later than 31 December 2011.

The following evaluation criteria will apply:

- Project leader should be a health professional
- Involvement of at least three European countries
- Scientific value
- Implementation and relevance for EULAR Health Professionals (i.e., how the project may improve the non-pharmacological management of patients in a short and/or long-term perspective, and/or whether the project may foster the development of a research network of relevance for the future beyond the period of the project)
- Quality of the work plan and methods
- Feasibility of the study within the planned timeframe
- Patient-centered approach (if applicable)
- Budget realistic for the planned project
- Planned dissemination and implementation of the research results

More information at:

http://www.eular.org/health_professionals_research_grants.cfm

Experiences from implementation of an evidence-based intervention in rehabilitation

Exercise is a common non-pharmacological and non-surgical treatment strategy in rheumatoid arthritis (RA). Dynamic exercise therapy in RA has been studied extensively, and proven to be effective in enhancing cardio-vascular fitness, muscle strength, physical and mental functioning, and quality of life, without detrimental effects on disease activity or radiological joint damage. As a result, exercise therapy is recommended in many sets of clinical guidelines and recommendations on the management of RA.

Between January 2005 and December 2007, an implementation study comprising a comprehensive evaluation of the dissemination and implementation of the RAPIT program (Rheumatoid Arthritis Patients In Training) in 4 selected regions in the Netherlands was conducted. The RAPIT program is a group exercise program consisting of supervised aerobic and muscle strengthening exercises, with a frequency of two times per week and a duration of 12 months. It proved to be more effective than usual care with regards to physical capacity and physical and psychological functioning in a randomized, controlled trial. In this implementation study, the barriers and facilitators for the implementation of specific exercise programs for people with RA on a larger scale were described. In the following I will present some of the main results and conclusions.

Enrolment and practical obstacles

Over an enrolment period of 24 months, 223 informed patients made inquiries on the program, of which 73 (33%) did not start, mostly because of the travelling distance to the practice. Eventually, 150 patients started with the program, which was by estimation a reach of 2.0% in the target population. Thirty-six patients ended the exercise program prematurely. The mean (Standard deviation, SD) attendance rate per patient was 55% (23%).

The relatively low reach in the target population is comparable with the proportion of about 1% that can be extrapolated from the implementation studies of the AFAP (Arthritis Foundation Aquatic Program) and PACE (Patients with Arthritis Can Exercise) program, developed by the Arthritis Foundation in the United States. There are a number of possible explanations for the low number of participants that were already also identified in previous studies. An attendance frequency of two times per week is time-consuming. As the program was provided during working hours, patients with a day job may not have been able to participate. The distance from the patient's home to the physical therapist's practice may also have played a role. Moreover, health insurance companies only funded the program for patients with a supplemental insurance package. In the Netherlands, there is a single statutory basic healthcare insurance policy for everyone. The statutory basic health care insurance covers the costs of basic medical care. Healthcare insurers offer supplementary packages to cover the cost of additional healthcare which may or may not include reimbursement of individual or group exercise therapy.

Attainable goal

The patients' reasons for not starting with the Rheumatoid Arthritis Patients in Training (RAPIT) program, for ending the program prematurely and the overall relatively low attendance rate in this implementation study suggest that engagement in intensive exercise therapy twice a week may not be an attainable goal for many RA patients. The very low proportion of RA patients participating in a supervised exercise program with a frequency of two times a week suggests that the attainment of physical activity at a moderate intensity level, incorporated in daily activities, could be a more realistic target of future interventions. For RA patients, this would have the advantage that patients with cardio-vascular co-morbidity as well as patients with weight bearing joint prosthesis could also engage in this type of exercise. Currently, research into the health benefits of moderate intensive exercise programs as compared to vigorous intensity programs in patients with RA is lacking. In addition, these findings highlight the need for studies on more effective patient recruitment strategies.

Effects on real life

Regarding the programs' effectiveness in real life, it is difficult to draw an overall conclusion from this study. Except for the positive effects on muscle strength, effects on aerobic capacity, functional ability, and psychological functioning as found in the original randomized controlled trial could not be substantiated. A possible explanation may be insufficient intensity, as in 6 providers the intervention was not appropriately carried out with respect to its intensity. This may have had an impact

on the improvement in functional capacity. Indeed, it was found that patients exercising in groups with higher quality showed more improvement in physical functioning. The self-reported disease activity scores did not significantly change over time, indicating that the intervention did not exacerbate the disease activity.

Motivated stakeholders

As regards the adoption of the program by stakeholders, it can in part be considered a success; a considerable proportion of all stakeholders supported the implementation. Sixty-eight percent of the participating rheumatologists did actually refer one or more patients to the program, a sufficient number of providers were recruited to offer the program in the four regions, and all local patient organisations brought the program to their members' attention. However, with respect to adoption by health insurance companies it should be noted that, although they were all willing to fund the program, reimbursement was limited to 12 months.

Lessons learnt

In general, the limited-scale implementation of an intensive exercise program for RA patients as described in this study can be considered moderately successful. The reach of the program was fair; however, this study concerned a first implementation attempt with limited project duration. On the other hand, adoption and implementation quality



F.J. van der Giesen would like to open discussion on experiences regarding the implementation of health professional intervention successfully, time- and cost-effectively.

F.J. van der Giesen
PT, PhD, MPA i.t
Department of Rheumatology
Groene Hart Ziekenhuis
Gouda, The Netherlands

of the intervention were relatively good. Both the limited effectiveness and the lack of data to draw conclusions regarding actual maintenance in the future however warrant additional research.

This research project was funded by the Dutch Arthritis Association (Grant no. IMP-03-1).

The program in a nutshell

Prior to the start of the program, the providers received a three-day training course and during the execution of the program, the quality of the intervention, as delivered by the providers, was measured on a quality scale from 1 to 15 (higher is better). Five of 12 providers who started one or more groups obtained the maximum possible total score of 15 points, 4 providers had a score between 11 and 14 points and 3 providers a score of 10 points or less. Attendance rate and quality of the program were significantly associated, with a higher mean attendance rate in patients treated in the high quality practices (61%, SD 18) than in the practices with sub maximal quality (51%, SD 24) (p=0.015). These results highlight the need for adequate provider training when considering program implementation in real life.

Regarding the future of the program, all providers were willing to continue with the program, provided that health insurance companies maintained the funding and that there would be sufficient number of participating patients. The provider of the training course confirmed the availability of the training course in the future. On the patient level, it was observed that the majority of patients that finished prematurely did so during the first 6 months. None of the 10 health insurance companies could answer the question "will you continue to fund the program in the future?", due to the rapid changes in health care funding policy on government and insurance company levels in the Netherlands.

London

25-28 MAY 2011

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The Health Professional Programme

Session type	Session title
HP Session	<ul style="list-style-type: none">• Ankylosing Spondylitis: The impact of AS on patient and society• Health promotion for people with chronic rheumatic diseases – an issue for health professionals?• Improving work conditions for people with musculoskeletal conditions• Multidisciplinary team care for rheumatic conditions – current status and future trends• Psycho-educational interventions for patients with arthritis and their families• The role and challenges of patient-reported outcome measures in health care research• What do nurse specialists do and how should they work to provide cost-effective healthcare?
Joint HP/Clinical/PARE Session	<ul style="list-style-type: none">• Chronic pain management: A person-centered, multidisciplinary approach• Innovating care by using patient's expertise
Joint Workshop Session	<ul style="list-style-type: none">• Is Tai Chi good for me?• Physical inactivity in patients with RA• Lets talk some more about sex• Patient safety: The unique challenges of musculoskeletal disorders• The expanding international attention to rheumatic and musculoskeletal diseases
Practical Skills Session	<ul style="list-style-type: none">• Ultrasound for health professionals – inflammatory arthritis

