



Issue 4 • 2018 Autumn

HPR News

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fighting rheumatic & musculoskeletal diseases together

Newsletter of the Health Professionals in Rheumatology

Delivering real change: EULAR's 5-year strategy

The EULAR Annual European Congress of Rheumatology 2018 saw the official launch of EULAR's new five-year strategic objectives. The *EULAR Strategy 2018-2023* is designed to further enhance the excellent standards and activities established, and led, by EULAR across the rheumatology field. It focuses on delivering real change by supporting the implementation of best practices and treatments.

Far-reaching benefits

"This is the third EULAR Strategy and it aims to close the gap between cutting-edge science and day-to-day care for patients with musculoskeletal diseases (RMDs)," said Prof. Johannes Bijlsma, EULAR President and Professor of Rheumatology at University Medical Centre, Utrecht in the Netherlands. "The impact of the six EULAR strategic objectives could have far-reaching benefits

for humanity: Many people may be able to work again, symptoms could be recognised quicker through better education in the field, and leading scientific research would be delivered in a compelling way that contributes to future thinking. The future holds promise, and the EULAR Strategy holds the action required to let this promise translate into action."

Challenging the stigma

Annette de Thurah, Past Chair of the EULAR Standing Committee of Health Professionals in Rheumatology (HPRs), welcomed the clear focus of the strategy. "This will enable HPRs to work closely together, and with the other two pillars of EULAR, to make a real difference to the lives of people with RMDs through research, advocacy, and the development and implementation of quality of care frameworks," she



Prof. Johannes Bijlsma

The EULAR Strategic Objectives 2018 - 2023

- 1. ESOR** - By 2023, EULAR will be the leading provider of education in rheumatic and musculoskeletal diseases (RMDs).
- 2. Congress** - By 2023, EULAR will provide the foremost RMD congress experience, building on the heritage of our outstanding annual meeting.
- 3. QOC** - By 2023, EULAR will deliver pre-eminent comprehensive quality of care (QOC) frameworks for the management of people with RMDs.
- 4. Research** - By 2023, EULAR will have established a European centre for RMD research to advance high quality collaborative research.
- 5. Advocacy** - By 2023, EULAR's activities and related advocacy will have increased participation in work by people with RMDs.
- 6. Governance, Infrastructure, Financials** - By 2023, EULAR will have established governance, workflows and infrastructure to deliver the EULAR strategic objectives.



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Annette de Thurah

said. "We can also better support HPRs through education and networking, and I would urge people to sign up to the EULAR School of Rheumatology."

In advocacy, EULAR will focus on the effect on people's working lives with the aim of keeping more people with RMDs in work by 2023. "HPRs can do much to challenge the stigma of RMDs and to support people with RMDs to secure or retain work," added Annette de Thurah.

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Apply now: EULAR HPR research grant

Every year EULAR funds one health professional research project in the field of rheumatic and musculoskeletal diseases (RMDs) that is in line with the mission, objectives and goals of EULAR. Projects will be funded up to a maximum of EUR 30,000. Application is now open!

More information can be found on the EULAR website at eular.org/health_professionals_research_grants.cfm

The application deadline for the 2019 HPR Research Grant is 7 December.



Role of physical activity for people with RMDs

By Anne-Kathrin Rausch Osthoff from the Zurich University of Applied Sciences

The [2018 EULAR Recommendations for physical activity in people with inflammatory arthritis and osteoarthritis](#)¹, as well as the meta-analysis that informed the recommendations by evaluating the effects of exercise and physical activity promotion in people with inflammatory arthritis and osteoarthritis², were published in summer 2018 and presented at the EULAR Congress in Amsterdam.

The meta-analysis, including 49 RCTs (3,909 people with rheumatoid arthritis (RA), spondyloarthritis (SpA), hypertrophic osteoarthropathy (HOA) and knee osteoarthritis (KOA)), showed a moderate effectiveness of aerobic exercises and resistance training on cardiovascular fitness and muscle strength. Physical activity (PA) promotion interventions produced a small increase in PA behaviour. No evidence was found for the effects of combined strength/aerobic/flexibility exercises and almost no literature was available evaluating neuromotor exercises. However, PA had no detrimental side effects like increased disease activity in any exercise dimension.

Recommendations are a milestone

Thus, the recommendations are a milestone for PA promotion in people with rheumatic and musculoskeletal diseases (RMDs)



as they confirm that the general PA recommendations³, including the four exercise dimensions (aerobic, muscle strength, flexibility and neuromotor exercises), are applicable (feasible and safe) to people with inflammatory arthritis (iA), including RA and SpA, and osteoarthritis (OA) as much as to healthy people.

Therefore, recommendation 1 states that exercise and PA promotion should be an integral part of the standard care throughout the course of the disease in people with iA and OA. Further recommendations state that all healthcare providers (MDs and health professionals in rheumatology (HPRs)) should take responsibility for promoting PA and should collaborate to ensure appropriate PA interventions by competent providers. For the individual, actual PA should be evaluated (type, intensity, frequency and duration) to identify which of the exercise dimensions can be targeted

for improvement, based on a clear personal aim.

PA plays a crucial role in care of people with RMDs

The recommendations draw attention to the crucial role of PA in the care of people with iA and OA, and support HPRs considering important aspects in the context of PA promotion. The recommendations will guide the development of future PA interventions and will facilitate upcoming research projects. Currently, the lay version is being developed.

Future projects are planned, including the translation into other European languages and the development of health system-specific implementation strategies. For example, in Switzerland, a project was developed together with the Swiss AxSpA-patient organisation to implement the general PA recommendations³ in the SpA exercise groups. The project is currently being pilot-tested.

1 Rausch Osthoff A-K, Niedermann K, Braun J, et al. 2018 EULAR recommendations for physical activity in people with inflammatory arthritis and osteoarthritis. *Ann Rheum Dis*. 2018 Sep;77(9):1251-1260. doi: 10.1136/annrheumdis-2018-213585. Epub 2018 Jul 11

2 Rausch Osthoff A-K, Juhl C, Knittele K, et al. Effects of exercise and physical activity promotion: meta-analysis informing the 2018 EULAR recommendations for physical activity in people with rheumatoid arthritis, spondyloarthritis and hip/knee osteoarthritis. *RMD Open*, accepted 28th August 2018

3 Garber C, Bissmer B, Deschenes M, et al. Quantity and Quality of exercise for developing and maintaining cardiorespiratory, musculoskeletal, and neuromotor fitness in apparently healthy adults: guidance for prescribing exercise. *American College of Sports Medicine Position Stand*. *Med Sci Sports Exerc*. 2011 Jul;43(7):1334-58. doi: 10.1249/MSS.0b013e3182131efb.

Get in touch

Welcome to the Autumn 2018 *HPR News*. Given that EULAR's new five-year strategy includes a focus on work, this issue includes a number of articles looking at the role of health professionals in rheumatology (HPRs) in supporting people with rheumatic and musculoskeletal diseases (RMDs) in work.

Read about two of EULAR's new recommendations and its new position paper on health and safety at work.

We turn the spotlight on the 2018 EULAR Annual European Congress of Rheumatology in Amsterdam as HPRs share their highlights with you.

You will find reports of two EULAR educational visits on pages 14-17. Will Gregory visited the Karolinska Institute in Stockholm while Maria Bergström went to the Medical University of Vienna's Centre for Medical Statistics, Informatics and Intelligent Systems.

If you have any ideas for future articles, don't keep them to yourself. Email me at kate@katebetteridge.me.uk



Do you have good news for the newsletter?

Ever since 2000, the HPR newsletter has provided the main information channel of health professionals in rheumatology within Europe. The newsletter is published twice a year, featuring the work of health professionals and all aspects of multidisciplinary collaboration. Please share tips about health professionals theses, projects and new research themes in the musculoskeletal field. Prescribe the newsletter free of charge to colleagues at www.eular.org/health_professionals.cfm

Towards implementation of patient-centred pain management

By Prof. Dr. Rinie Geenen, PhD from the Utrecht University, Department of Psychology

The [EULAR Recommendations for the health professionals' approach to pain management in inflammatory arthritis and osteoarthritis](#) were recently published in the EULAR Journal, the *Annals of the Rheumatic Diseases*. It is now up to Europe's leading health professionals in rheumatology (HPRs) to bring the recommendations to the attention of their own nations – and to use them in clinical practice.

A patient-centred framework

EULAR considered the development of evidence-based recommendations to be essential because pain is the predominant symptom for people with inflammatory arthritis and osteoarthritis. Knowledgeable pain management support is expected to reduce pain, and increase functioning and well-being. As a consequence, individual and societal costs will be reduced.

A unique feature of the project was that a multidisciplinary task force, which included patient representatives, adopted a patient-centred framework within a biopsychosocial perspective. Relationships between all factors of a biopsychosocial model of pain are recognised to be interactive and reciprocal, with mutually influencing pathways being similar to a hanging mobile toy, in which movement of one part causes movement of other parts.

Patient preferences and priorities

Because the importance of the distinct factors differs between individuals, any treatment is guided by scientific evidence in combination with the assessment of patient needs, preferences and priorities. These include pain characteristics; previous and ongoing pain treatments; inflammation and joint damage; and psychological and other pain-related factors that might need attention. Examples include:

- a) the nature and extent of pain-related disability
- b) beliefs and emotions about pain and pain-related disability
- c) social influences related to pain and its consequences
- d) sleep problems
- e) obesity.



This assessment by HPRs is brief or extensive depending on factors such as available time, whether it is a first or regular consultation, and the needs of the patient.

Pain treatment options typically include education complemented by physical activity and exercise, orthotics, psychological and social interventions, sleep hygiene education, weight management, pharmacological and joint-specific treatment options, or interdisciplinary pain management. Effects on pain were shown to be most uniformly positive for physical activity and exercise interventions, and for psychological interventions, while effects on pain for other interventions were shown for particular disease groups. The task force unanimously endorsed that, in rheumatology care, besides pain severity, physical and psychological functioning are major outcomes of any management intervention by HPRs.

Turning recommendations into clinical practice

The task force hopes that the recommendations turn out to be workable and

effective in clinical practice. The first signs are positive. Publication of the recommendations yielded 150 tweets and several shares by news outlets and Facebook pages (source: Altmetric.com). Reactions in the field were generally positive; especially regarding the biopsychosocial model including lifestyle interventions and the patient-centred approach.

Expert opinion

It is now up to the leading HPRs in Europe to bring the recommendations to the attention of health professionals, including rheumatologists, in their countries and to use them in clinical practice. The article in the *Annals of the Rheumatic Diseases* offers all necessary information about evidence for specific interventions as well as considerations based on the expert opinion of the task force.

2019 EULAR Congress

Registration for the EULAR Annual European Congress of Rheumatology 12-15 June 2019 in Madrid, Spain is now open. Register before 31 January 2019 to take advantage of the early registration fee.

Abstract submission is open until 23:59 CET 31 January 2019. Visit congress.eular.org/abstract_submission.cfm for details on how to submit. Each year, EULAR awards a number of travel bursaries to the first presenting author of an abstract accepted for oral or poster presentation. A bursary facilitates attendance at the EULAR Congress and includes free registration, three nights' hotel accommodation and EUR 350 for travel and living expenses. Make sure to apply for a bursary at congress.eular.org/health_professionals.cfm when submitting your abstract.

Countries support Don't Delay, Connect Today

YES WE DID IT 🎉. The Run To Connect event during the Ostend Night Run was a great success and a night to remember. With more than 70 enthusiastic people we gave visibility to dreams and to the Don't Delay, Connect Today campaign of eular.org. YES WE DID IT 🎉 #ConnectToday



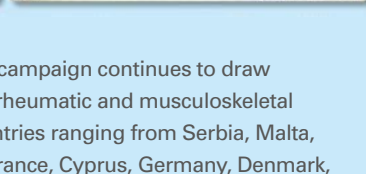
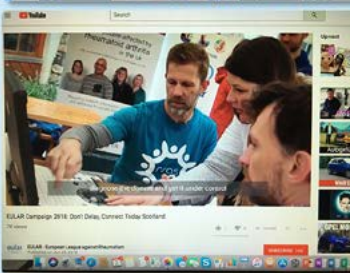
World Arthritis Day @ArthritisDay - Sep 11
Be inspired by the #ConnectToday campaign in Serbia, which promoted the message of early diagnosis of RMDs in a press conference to the media. Find out more and be inspired by their campaign by visiting: bit.ly/2wDn8Ph



EULAR Campaign 2018: Don't Delay, Connect Today Scotland



13 EULAR Retweeted
World Arthritis Day @ArthritisDay - Oct 4
Over 120 million people in the EU are affected by RMDs. Help us raise awareness about early diagnosis and timely access to the appropriate treatment by joining the EULAR campaign "Don't Delay, Connect Today" #ConnectToday #TimeForChange



EULAR's Don't Delay, Connect Today campaign continues to draw awareness to the potential impact of rheumatic and musculoskeletal diseases (RMDs) across Europe. Countries ranging from Serbia, Malta, Romania, the Netherlands, Finland, France, Cyprus, Germany, Denmark, Poland, the UK, Belgium, Georgia, Slovenia and even Saudi Arabia have launched campaigns nationally and locally, bringing together patients, physicians, health professionals in rheumatology (HPRs) and policy makers.

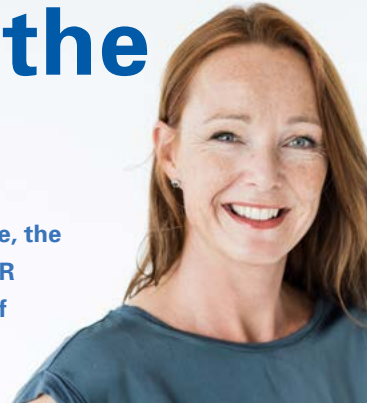
Don't Delay, Connect Today aims to raise awareness of the importance of early diagnosis in preventing further damage to those living with RMDs and promote timely access to evidence-based treatments.

To find out more, visit

eular.org/what_we_do_dont_delay_connect_today_2018.cfm

From the Chair

From Rikke Helene Moe, the new Chair of the EULAR Standing Committee of Health Professionals in Rheumatology



Powerful and skilled EULAR health professionals in rheumatology (HPRs) were visible in Amsterdam during the 2018 annual congress. They presented high levels of communication, educational and research skills, evidence-based treatment, prevention and multidisciplinary approaches to support people with rheumatic and musculoskeletal diseases (RMDs) to participate fully in life.

"We need to support each other to assist good collaboration"

HPRs are continuously collaborating with people with RMDs and rheumatologists. We need to support each other to assist good collaboration and achieve high-quality accomplishments. At the congress networking event – and all week! – I observed colleagues asking each other advice, and making plans to learn from each other and form resource groups. People were inviting each other to join different Study Groups, talking about educational visits and exchanging email addresses to ask each other's advice regarding rare diseases. I even heard people posing questions about the possibility of forming a national HPR organisation – there are still many countries who do not have their own.

"HPRs possess substantial knowledge"

An increasing amount of people are diagnosed with RMDs, and HPRs possess substantial knowledge and clinical expertise to help meet this challenge and contribute significantly to achieving better lives for people with RMDs. We aim to reduce the individual and societal burden of RMDs in the future.

The breadth of activity within EULAR is growing, and we will continue our representation across all of EULAR's activities. We will keep on developing projects and strategies through our Educational and Scientific Sub-committees. We are so proud of our HPR classroom and the expanding possibilities that the EULAR School of Rheumatology presents. We are also very proud of how our national HPR member organisations continue to grow.

The HPR leadership also follows up on facilitating a high-quality congress programme, with abstract scoring, Study Groups, Task Forces, bursaries, grants and prizes. Thank you to all HPRs who contribute to this work – for all the engagement, proposals and new ideas.

Hang in there! Trust each other's knowledge. Notice each other. And share what you are brilliant at!



Working towards greater collaboration



Committee members of EULAR's Health Professionals in Rheumatology and the American Association of Rheumatology Health Professionals met together in Amsterdam

Looking back at this year's EULAR Congress in Amsterdam, a main highlight for me was seeing the large number of enthusiastic health professionals in rheumatology (HPRs) networking and taking part in high quality scientific and clinical discussions. In addition to all the telecalls, virtual conferences and digital discussions that we are all involved in during the year, face-to-face meetings with our dear EULAR friends at the annual congress are always very special!

The EULAR HPR network has been growing and we continue to reach out. We are delighted to be able to meet our American friends at the EULAR Congress each year. For a few years now, an American-European HPR session has been repeated at both the EULAR and ACR congresses – it is a good way to link with HPRs from the USA and Europe.

Congress planning

The EULAR Congress programme is set up by the EULAR Scientific Programme Planning Committee, in close collaboration with PARE. Next year's programme has already been assembled, and I would like to take this opportunity to thank all the people who have contributed by submitting a session proposal. You have given us a lot of valuable input which, with some modifications, has been taken up by the Scientific Programme Planning Committee.

One specific type of session is the joint sessions which are organised with PARE and the

rheumatologists. They are typically very well attended and are of interest to a wide range of conference participants. We are looking forward to a number of interesting sessions at next year's; and hope to meet many of our dear friends again!

Meanwhile, some of you might have attended the ACR Conference and I would like to use this opportunity to congratulate Christina Opava on the award presented to her by the American Association of Rheumatology Health Professionals in recognition of her role in achieving collaboration between our two HPR organisations.

Working with PARE

I am even more convinced that PARE and HPRs should work together more closely in the future, not only in terms of common sessions at our annual congress, but both on an individual basis and an organisational level. This will drive the future of rheumatology care in Europe. Co-operating with PARE makes us stronger in convincing politicians and policy makers to fund our research proposals.

An important area where PARE and health professionals need to work together, in my opinion, is work. Productivity and paid work are essential activities of daily living and constitute a fundamental right of humans. What can health professionals offer patients with RMDs in the area of work and occupation?

Productivity and paid work are also the core topics of our new newsletter and were an important topic at the World Arthritis Day conference in Brussels at the beginning of October.

Support in the workplace

HPRs do, of course, already support people with RMDs at their workplace by various different methods, advice and interventions. The benefits of HPR support for people with RMDs in relation to work and occupation has convinced politicians in Brussels about the importance of non-pharmacological interventions to keep people healthy. In our newsletter we will address this topic from various perspectives. We are looking into concrete experiences of patients, and into methods and implementation regarding the quality of care.

Implementing equally high quality of care in European countries is one of the new [strategic aims of EULAR](#). We look forward to hearing your ideas on how to successfully implement improved quality of care in daily practice, especially in the area of work and occupation. We are convinced that people with RMDs will benefit from a lot of HPR activities in this area and we will attract many new health professionals who have not been so far involved with EULAR.



Tanja Stamm



With work such a major focus for EULAR, Tanja Stamm talks to our *HPR News* editor Kate Betteridge about how rheumatoid arthritis influenced her career choices and asks her thoughts on the HPR role in supporting people to stay in work

What were your first thoughts on being diagnosed with a rheumatic and musculoskeletal disease (RMD) as a young girl?

I was 13 when I was diagnosed and I thought it was a joke. I remember saying that stereotypical phrase: "But only grandparents get arthritis". The seriousness only sank in a few weeks later when the inflammation had taken hold and I was unable to manage getting around school – many of my classes were upstairs and long distances apart. I wasn't able to attend school for two years and needed home tutoring. I soon realised that arthritis did not respect age! I became quite depressed and isolated being stuck at home.



Kate with her mother before her diagnosis

What would you advise young people with RMDs to consider regarding their professional careers?

There are more options these days for how a person can do a job, many of which can really help people with RMDs – remote or flexible working, increased use of technology for example. I'd advise people to gain paid or voluntary experience to increase their chances in the job market. Building up a portfolio of transferrable skills will stand most people in good stead – and remember that managing an RMD teaches many management skills which translate into working life. I'd recommend taking advantage of training courses and keeping skills up to date. It's important to know your strengths and what is important to you. Be bold and brave – even when you don't feel it!

Which kind of career decisions and occupational choices did you take?

Books and writing were always something

that featured in my life, so I wanted a career that involved words. Law or journalism were my two preferred options. I knew that I had physical and pain-related limitations so, even within those two career options, there would be certain roles that might exclude me. An outside broadcast journalist spending time on your feet in the pouring rain would not be ideal!

I did some work experience during a summer holiday in a solicitor's office and found the work really dull. Not long after, I won a competition to work on Wales's national newspaper for a week producing a youth supplement. Aged 17, I found myself away from home, coping with my RMD by myself for the first time, working in a real-life situation which had consequences if I didn't get things right. It was brilliant! That experience gave me my confidence and independence back, and it also shone the light on the right career for me. I researched the different types of journalistic roles and realised that writing about health issues was what I wanted to do.

Did you tell the person you work for that you have a rheumatic disease?

Luckily, I went straight from university to work at a national UK arthritis charity. I disclosed my RA from the outset and always received excellent support. I chose to tell all of my colleagues and my immediate team couldn't have been more supportive. I realise I have been very fortunate. Many people with RMDs lack support and face discrimination. I'm glad campaigns like Don't Delay, Connect Today are helping to increase understanding of RMDs which will help people in the future.



Aged 16: With her father before her RA was under control



Her first 'Tweet up': Kate (centre) with friends from around the world at the 2018 EULAR Congress

What support from health professionals do you consider important regarding being able to work?

Helping people to remain functional, both physically and emotionally, is an incredibly important role which HPRs perform. This can be a hand therapist showing exercises to keep hands and arms flexible enough to use a keyboard or perform regular tasks, an occupational therapist giving advice on ergonomic chairs, physios giving advice on keeping muscles strong, podiatrists making insoles to help walking, nurses giving advice on sleep or psychologists offering support for our emotional well-being.

What could be done differently?

Support is not necessarily provided automatically or at the right time – and often people with RMDs do not know what support is out there or how to access it. Helping people to better navigate the system would be such a help.

While I am ever grateful of the support, I often wish appointments were scheduled on the same day or there was an opportunity for some to be done remotely using interactive technology. I can't tell you how much pain, expense, time and stress it would save people if travelling was reduced. And it would make such a difference to people who find it difficult to take time away from work or family responsibilities.

Finally, I would like to see pain being given a higher priority. It can affect people's mental health, their confidence to take part in social activities and prevent them working.

What do you consider your biggest achievement in life so far?

When I started out, my goal was to be able to do a full-time job. And I have succeeded in that! But, really, I am proud that the information I have written and developed has helped people make positive choices about, and changes to, their lives. Being steeped in the views of thousands of people with RMDs has enabled me to convey issues that affect people on a daily basis to consultants, health professionals, decision makers and industry. Knowing that I have helped to make a difference matters enormously to me.

There was one magazine article I wrote to help people safely and confidently plan a holiday with their RMD. A few months later an 82-year-old lady rang to tell me how she had followed the advice in the article and managed to travel by herself from the UK to visit her grandson in Russia. That made me feel very proud.

Did you ever consider voluntary work?

I have always done voluntary work – even as a teenager. These days I volunteer for World Arthritis Day, I'm a member of my London borough council's Disabled People's Commission and I'm a trustee of a local disabled people's organisation. It's important to ensure I maintain a balance between paid work, voluntary work and my social life. It is very easy to over commit and feel I am letting people down when I am having a flare up for example. Pacing myself is essential – even if it isn't always successful!

I would advise people to identify organisations or causes they are interested in so that they can share their skills and expertise. We all have a

lot to give and volunteering gives a lot back! It's also a great way to meet people and make new friends.

What would you like HPRs to know about you and your life with an RMD?

I always try to be positive, but every day is a challenge. Managing pain, fatigue, brain fog, cats, cooking, going to the gym, making a presentation, editing articles, attending hospital appointments, going to the cinema and visiting friends is exhausting. Okay I might not attempt all of those in one day, but you get the picture. Life is complex and full!

What matters is being able to do the things I want to do. Having an open discussion with your patients about their goals will help identify areas where they need help and support. It's then so much easier to work together to find solutions or adaptations.

I'd also like to say thank you as I might not be still working full time now if it wasn't for the many HPRs who have supported me over the years!

See PARE's article about working with an RMD on page 12.



With husband Neil at the 2015 EULAR Congress in Rome

EULAR Congress 2018

From dancing La Macarena to learning about wearable technology, health professionals in rheumatology had the opportunity to get involved in a range of meetings, sessions and activities during this year's EULAR Annual European Congress of Rheumatology in Amsterdam. Yvonne van Eijk-Hustings and Fernando Estévez-López share their HPR Congress highlights



Yvonne van Eijk-Hustings

Yvonne van Eijk-Hustings, Senior Researcher and Rheumatology Nurse, the Netherlands

This year's health professionals' in rheumatology (HPRs) programme was diverse and addressed different topics from various perspectives. The HPR Welcome Session provided the opportunity for all HPRs to connect and start a multidisciplinary experience. The Highlights Session, the very last session of the Congress, provided the opportunity to receive an overview of the many topics. In between, two joint sessions with PARE, an HPR project session, and eight thematic sessions completed the HPR programme. Moreover, there were 116 posters and two guided poster tours.

"Working was an unachievable goal for most people"

We aim to provide clinicians and basic/clinical researchers with a range of heterogeneous opportunities and tools to improve skills and to establish contacts with peers and mentors from across Europe. EMEUNET members are also integrated in EULAR Task Forces as full members, selected via a competitive process based on their background and research interest.

None of these objectives could be fulfilled without the work and enthusiasm of the people involved in the seven sub-groups that form the Working Group of EMEUNET: Education, Peer Mentoring, Newsletters, Social Media, Visibility, Country Liaisons, and Global Affairs. EMEUNET sub-groups are enthusiastically engaged in several activities, and the list of current and upcoming projects has quickly expanded over the past few months.

When I entered the room before presenting the HPR highlights to PARE, the session on "Work and rehabilitation – key priorities for people with RMDs" was still going on. It is great that we can talk about such an important topic and that it is an issue nowadays – working was an unachievable goal for most people with rheumatic and musculoskeletal diseases (RMDs) when I started my work as a rheumatology nurse.

It is clear that maintaining work capacity requires effort from people with RMDs and many HPRs, and that activities at a country level are necessary. The starting place within rheumatology is preventing damage and functional problems that can result in work loss. Therefore, the session on delay in treatment was very important. Various forms of delay were presented. Patient delay seems symptom dependent, but is also influenced by coping strategies and illness beliefs (Stack-SP0030, van der Elst-SP0031, and Makri-SP0032). GP delay is influenced by (lack of) knowledge (Fautrel-SP0033). Rheumatologist delay is caused by limited access to rheumatologists. The consequence of delay is huge: no (or no easy) remission (Bartlett-OP0106).

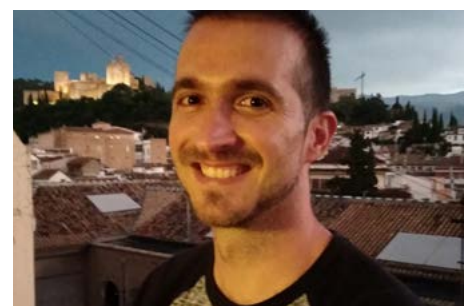
Solving delay requires multifaceted interventions, and there is a role for HPRs: increasing knowledge and raising awareness but not anxiety.

"Supporting people with RMDs requires a joint effort"

Another major topic was lifestyle, for example exercise, smoking cessation, good sleep. The sessions showed that physical activity is very

important – much more than exercise – as was reflected by the presentation of Zhivko Yankov from Bulgaria on the patient's perspective on physical activity. He presented good reasons for being active and told the audience that much is about integrating activity in daily work. However, how to start and how to get motivated are big questions. Supporting people with RMDs in adopting a healthy lifestyle requires a joint effort between HPRs and people with RMDs.

Despite all the specific topics, an overarching sense of "togetherness" remains after the Congress. Acting as a team is the big challenge for HPRs, together with people with RMDs and the physicians.



Fernando Estévez-López

Fernando Estévez-López, Postdoctoral Researcher, Spain

An innumerable number of interesting topics were emphasised in this year's HPR programme. I will focus on the importance of: (i) working together, with and for people with RMDs, (ii) paying attention to the individual characteristics of people with RMDs, (iii) when possible, moving healthcare from on-site settings to online environments that are accessible to everyone and (iv) engaging in



EULAR Congress 2018: The HPR sessions were well attended

exercise or physical activity in order to enhance quality of life of people with RMDs.

Gjønnes et al. (FRI0721-HPR) showed the experience of including people with RMDs as researcher partners (co-researchers) in an interdisciplinary team. The team aimed to provide a personalised handwritten consultation as a tool for conveying information beyond the walls of a rheumatology consultation room. The experience was positive, as highlighted by participants' statements such as: "This is the first time I have walked out of a doctor's office... knowing what to do" and "It's [like] a manual for your car: if something goes wrong, you go to the manual and it's there". These findings reinforce the idea of working together with and for people with RMDs as a fruitful approach.

"Personality traits have a considerable influence"

Santos et al. (OP0160-HPR) examined the determinants of happiness health-related quality of life in people with rheumatoid arthritis (RA). Our colleagues from the Promoting Happiness Through Excellence of Care Group (Coimbra, Portugal) concluded that personality traits have a considerable influence on how impactful/disrupting patients perceive their disease to be, with decisive consequences on their quality of life and, also, on how happy they feel towards life. Along with other communications (e.g., Van Heuckelum et al., OP0281-HPR; and Van der Elst, SP0031), the take home message was that a "one-size-fits-all" approach is not realistic in the healthcare of people with RMDs.

Several presentations revealed experience of using information technology applied to healthcare, which is a promising approach for overcoming the limited scalability that traditional face-to-face healthcare presents. Renskers et al. (SAT0729-HPR) showed that online monitoring of inflammatory RMD symptoms helped patients became more aware of their disease and its consequences, as well as more independent of their healthcare provider. On the other hand, Zuidema et al. (OP0158-HPR) concluded that a tailored eHealth self-management programme was not effective for people with RA. A potential limitation of eHealth care is, as suggested by Rongen-Van Dartel et al. (OP0159-HPR), that people with RMDs may refrain from using a digital environment for diverse reasons. In a networking discussion, Prof. Rinie Geenen (Utrecht University, the Netherlands), suggested moving RMD care into online environments step by step, educating HPRs first

and walking people with RMDs to online settings later. Another important take home message was that eHealth is a complement to face-to-face not a substitute.

"A walking programme improved sleep quality"

Exercise was a topic of great interest for HPRs at the congress. Particularly interesting was to observe that very simple interventions may be enough to reduce symptoms of RMDs. For instance, in the pilot study presented by McKenna et al. (THU0716-HPR), a walking programme improved sleep quality for people with RA. In a meta-analysis, Davergne et al. (THU0745-HPR) concluded that providing people with RMDs with a wearable activity tracker lead them to increase physical activity by more than 1,500 steps per day.

Thomsen et al. (OP0219-HPR) performed a randomised controlled trial in people with RA. The intervention group received three individual motivational counselling sessions and a short message service (SMS) aimed at reducing daily sitting time over 16 weeks. Our colleagues from Copenhagen (Denmark) demonstrated that, even 18 months after completion, the intervention was effective for reducing daily sitting time. In fibromyalgia, Gavilan-Carrera (OP0076) provided preliminary evidence showing that a theoretical substitution of 30 minutes of sedentary behaviours with light physical activity may be related to better quality of life.

After a very busy time in Amsterdam, the attendees to the HPR Highlights Session joined me in some physical activity by dancing the famous Spanish song "La Macarena". It definitely helped us to replace sitting time with light physical activity!



Delegates at the HPR Highlights Session dance to La Macarena

Sandra Mintz, MSN, RN-BC, immediate Past President of the American Association of Rheumatology Health Professionals, shares her thoughts on the deepening collaboration between the two organisations

"The leaders of the Association of Rheumatology Health Professionals (ARHP) and the EULAR HPRs have a rich tradition of collaboration through joint publications, networking, and programming, particularly through the Congress. This affords a forum for EULAR HPRs leaders, Tanja Stamm, PhD, Annette de Thurah, MPH PhD, and Rikke Helene Moe, PhD, MSc, RPT to meet and interact with ARHP leaders such as Afton Hassett, PsyD, Hazel Breland, PhD, OTR/L, FAOTA and myself, to explore the varied healthcare settings and associated unique challenges each bring.



Sandra Mintz

Through these interactions, a broader awareness and understanding creates opportunity to

strategise and envision solutions to issues identified in sessions such as the Sustainable Healthcare held at the EULAR 2018 programme. This well-received joint ARHP/EULAR session allowed us to learn from each other and identify how to best meet the needs of the global rheumatology community.

In addition to our joint key initiatives, ARHP was deeply honoured to be able to recognise Prof. Christina Opava with the 2018 ARHP Lifetime

Achievement Award at this year's October ACR/ARHP Annual Meeting in Chicago. We look forward to continued collaboration with our EULAR colleagues."



Health and safety at work

Yeliz Prior, University of Salford, United Kingdom, and Mathilda Björk, Linköping University, Sweden, introduce EULAR's new Position Paper on Health and Safety at Work

Growing evidence shows that rheumatic and musculoskeletal diseases (RMDs) are one of the most prevalent chronic conditions, affecting 1 in 4 people in Europe and accounting for 30% of all disabilities. RMDs are the leading cause of work loss, absenteeism, presenteeism and early retirement, representing 60% of all work-related problems with the total cost of work-related RMDs being estimated at €163bn. It is expected that the prevalence of the RMDs will increase with the growing trends in ageing and people having to work longer into older age.



Yeliz Prior



Mathilda Björk

to meet the needs of working people with RMDs with a holistic approach. Given the growing number of HPRs conducting internationally-leading research into the Patient Reported Outcome Measures for work and RCTs to better understand the relationship between RMDs and work participation, we are already on our way to meeting EULAR's recommendation of developing evidence-based approaches to prevent and reduce work loss in people with RMDs.

Rising prevalence

The [EULAR position paper](#) considers EU-level directives, policies, frameworks and initiatives on health and safety at work within EU and member states, and suggests a lack of co-ordination, knowledge, implementation and support across different countries. It points out that, despite all these policies and initiatives, the prevalence of work-related RMDs has increased in 21 member states and only decreased in five. Thus, it puts forward that it is time for the EU to take a strong approach to tackle the substantial burden of RMDs.

The position paper also identifies and discusses three main challenges, beyond the traditional focus on prevention and risk factors, that need to be taken up by national and EU policy makers:

- 1) prevention of RMDs in the work place
- 2) retention of people with RMDs at work
- 3) access to occupational health professionals and therapists.

Recommendations at EU level, member state level and for employers (and other stakeholders) are presented to meet these challenges.

Acting collaboratively

The position paper emphasises the fact that, whilst prevention of work-related diseases, such as RMDs, is recognised as a priority, the importance

of job retention to working people with RMDs, their employers and the impact on the economy needs to be equally recognised. Without the adequate retention and implementation policy, Europe risks losing a highly skilled workforce, which is required due to the ageing population.

There remains a mismatch between those who are keen to stay at work or return-to-work following sick leave or job loss, and the mechanisms allowing them to do so. The lack of employer support and workplace adaptation, coupled with the invisible nature of RMDs and the perceived barriers to accessing health appointments during working hours, remains a challenge for people with RMDs to keep working.

As EULAR is built on three pillars – PARE, HPRs and scientific communities – there is an opportunity to act collaboratively with all stakeholders to increase public awareness, patient education, health and workplace interventions, and guidelines for HPRs based on research evidence to prevent and reduce work-related issues in people with RMDs.

Meeting the needs of people with RMDs

Early and aggressive treatment with biologic medications and multi-professional interventions have allowed more people with RMDs to continue to work. Nevertheless, people with RMDs still experience pain, fatigue, sleep issues, cognitive difficulties and limitations in activities and participation. HPRs have the necessary competencies

HPRs taking an active role

It is of paramount importance that HPRs should prioritise work assessment and interventions in clinical practice to support people with RMDs who would like to retain employment or return-to-work following long-term sickness absence or job loss. HPRs can also take an active role in educating patients about current workplace policy and initiatives so that they understand their rights at work and liaise with employers when appropriate with regards to workplace accommodations.



Last but not least, HPRs play an important role in ensuring there is patient representation in research to further the evidence base regarding the prevention and reduction of work instability and disability in people with RMDs.

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For full details, visit eular.org/myUploadData/files/eular_position_paper_on_health_and_safety_at_work.pdf



RMDs under discussion in the European Parliament

By Neil Betteridge, International Liaison Officer, Public Affairs, EULAR



Interest Group on RMDs meeting

As the EU enters the final year of its current business period, with European elections taking place in May 2019, the institutions are busy finalising discussions on a number of legislative proposals. EULAR has, therefore, been extremely busy throughout 2018 promoting the needs of the rheumatic and musculoskeletal diseases (RMD) community across policy areas through its public affairs work.

The long-standing European Parliament Interest Group on RMDs, led by Roberta Metsola MEP, held two meetings in the first half of the year with a third planned for November. Each included discussion regarding the work of HPRs.

The first took place in February with the topic *"Advancing disability policies after the EU Accessibility Act"*. The meeting discussed the need for a comprehensive approach to adapting products and services to the needs of disabled people to enhance their social and economic inclusion.



Neil Betteridge

The second meeting took a practical look at the lives of people with RMDs in the workplace, discussing how the EU can improve and facilitate the economic integration of people with RMDs. The topic of the meeting was *"Safer and healthier work: Facilitating the integration of people with chronic diseases"*. Speakers highlighted the important role of policy makers and employers, but also health professionals such as occupational and physio therapists, in improving retention and return-to-work policies for the benefit of people with RMDs and other chronic diseases.



2018 Brussels Conference

Health innovation and the future of EU research policies

A defining topic throughout 2018, and for the remainder of the current legislative period, is that of Horizon Europe – the EU's 9th Research Framework Programme. The Commission's proposal kick-started discussions with policy-makers on how to guarantee a leading position for the EU in the global research landscape, with high priority given to health and well-being. EULAR has been successful in positioning itself at the centre of these discussions, not least by publishing a position paper on Horizon Europe and making recommendations to amend the proposed legal text to better represent the views of the RMD community.

In addition, EULAR organised its annual World Arthritis Day Conference this year on the topic of *"Bringing chronic diseases to the forefront of health innovation: From the lab to individualised healthcare"*. The aim was to develop policy recommendations to EU and national decision-makers on research and healthcare innovation

policy developments. A dedicated session during the conference took a strong HPR focus by discussing the organisational and human challenges in the introduction of digital solutions in healthcare services.

International collaboration

To further the EULAR strategic priorities around work, EULAR has recently met with key organisations to explore partnership working. Specifically, EULAR met representatives of the EU Agency for Safety and Health at Work (EU-OSHA) and the Federation of European Academies of Medicines (FEAM) during a visit to Brussels in June. The aim of the meeting with EU-OSHA was to discuss possible collaboration, particularly regarding the future EU-OSHA campaign on the prevention of RMDs at work (2020-2021). The purpose of the meeting with FEAM was to explore possible collaboration in research and innovation policies.



Alliance for Biomedical Research in Europe meeting

As part of EULAR's involvement and membership of the Alliance for Biomedical Research in Europe, EULAR Past-President Prof. Burmester (centre left) participated in a meeting with MEP Christian Ehler (centre) and Prof. Axel Pries (centre right), President of the BioMed Alliance at Berlin's Charité University Hospital.

The reports of the Interest Group meeting, World Arthritis Day Conference and position papers are available at eular.org.

Looking ahead, with work now the number one strategic priority for the public affairs team over the next five years, the already close relationship with HPRs is set to increase further. We greatly look forward to developing this together with you all!



Challenges of everyday life with an RMD



Keeping active is important: The Bulgarian Organisation for Patients with Rheumatic Diseases provides seminars on nutrition and exercises

Boryana Boteva, PARE Board member from Bulgaria, discusses the many challenges people with rheumatic and musculoskeletal diseases face in the workplace

Work is an important part of life for every person, including the lives of people with rheumatic and musculoskeletal diseases (RMDs). Staying active is essential and, nowadays, staying active is possible for people with RMDs thanks to the new medications that are available. Being active doesn't just include the opportunity to work, but also caring for family, doing voluntary work, travelling and meeting friends. All this is part of feeling like you are similar to others – like healthy individuals.

Working has many benefits

Working is not just a way of earning money. It also helps people to socialise and participate fully in everyday life. Although the new drugs on the market allow us to be active and to be able to work fully and equally with our other colleagues, we often face a lot of challenges that are not familiar to other, healthy, people. These include the need to adapt the workplace to our needs, the problems we face when travelling to the workplace and the need for more breaks in order to cope with the fatigue that we feel during the day.

Last but not least, I would like to mention the fear and the uncertainty that we feel when applying for a job. For those of us living in Eastern Europe, for example, we do not receive the understanding that we would like from employers, especially when

we have to be hospitalised, or even just for visiting the rheumatology clinic to pass the assessments for being prescribed biologics.

Getting employer support

As a person living with an RMD, I would like to share that, for me, working is as important a part of my life as it is for any other person. I would advise all people with RMDs to talk openly with their employers about the challenges they face. They should ask for an adapted workplace with a suitable chair, desk or computer, and request whether it is possible to arrange more breaks during the day.

Gaining new qualifications, improving skills and taking new, additional courses can help people with RMDs to adapt to the challenging environment and compete with others.

Furthermore, most of us have to take care of our families, home, garden and children – all of which require extra effort and exhaust our energy. New technologies, such as home cleaning robots, would be very useful or sharing household duties with family members.

HPR support

People with RMDs should be supported by health professionals in rheumatology (HPRs) in

all of these daily activities, such as occupational therapists, nutritionists and physiotherapists.

Unfortunately, in Eastern Europe, and especially Bulgaria, these are exotic specialties and it is very expensive to have access to a nutritionist for example.

HPRs have an important role to play in informing their patients about the type of workplace adaptations that are possible, teaching exercises which keep us stronger and more flexible and sharing ideas on improving our sleep patterns

so that we can concentrate better during work. HPRs can advise on managing around the house, on how to save our energy and protect our joints. All this can help us stay in paid or voluntary work for longer.

It is important for people with RMDs to continue to stay active and maintain good physical condition. Recognising the role that patient groups play in this is essential. You could encourage your patients to join different national patient organisations or local groups that can help them to stay active and share self-management tips outside of the clinic.

People with RMDs face many challenges in their everyday life. Patient organisations – in co-operation with HPRs and rheumatologists – do their best to help those people live independent lives, full of joy, happiness and fulfilment.



Boryana Boteva

Reaching out

EULAR continues to work towards growing its health professional network membership. We hear from a new member about the work of its association.

National HP member organisations of EULAR:

Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Hungary, Ireland, Israel, Italy, Malta, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, Switzerland, UK

● Visit the EULAR Health Professional [website](#) to find out how your country could apply for membership.

EULAR HPRs welcome Slovenia

By Milena Pavic Nikolic, President of the Slovenian HPR association

The Slovenian Association of Health Professionals in Rheumatology is a voluntary, independent and professional association of members who work in the field of rheumatology. It was founded in 2017 and nurses, physiotherapists and occupational therapists currently make up our membership.

The purpose of the Society is to promote the professional interests of members in the field and, thus, contribute to the development of rheumatology in Slovenia. We carry out the following functions:

- co-operate with organisations and institutions engaged in research in the rheumatology field
- strive for a high professional and ethical level of work within the Society
- inform members and the public about challenges and progress in our Society encourage the training of our members abroad and the exchange of experts at home and abroad
- develop and improve the knowledge of healthcare workers in the field of rheumatology
- promote co-operation of between the various healthcare workers.

We encourage members to increase their activities in the field of rheumatology, especially



Members of the newly-formed Slovenian Association of Health Professionals in Rheumatology

in research. Our annual meeting allows us to exchange experiences and knowledge and, for several years now, our nurses have been actively participating with EULAR.

Exciting opportunities

As new members of EULAR Health Professionals in Rheumatology we have a new and exciting opportunity to participate in international projects and to develop guidelines for patient treatment.

Last year we organised six professional meetings and created a website with useful links, educational and information materials and lectures from our meetings. In collaboration with our national organisation of patients with rheumatism, we joined EULAR's Don't Delay, Connect Today campaign. We were active at fairs, in health centres,

annual rheumatology meeting etc. The first feedback from visitors and listeners has been encouraging.

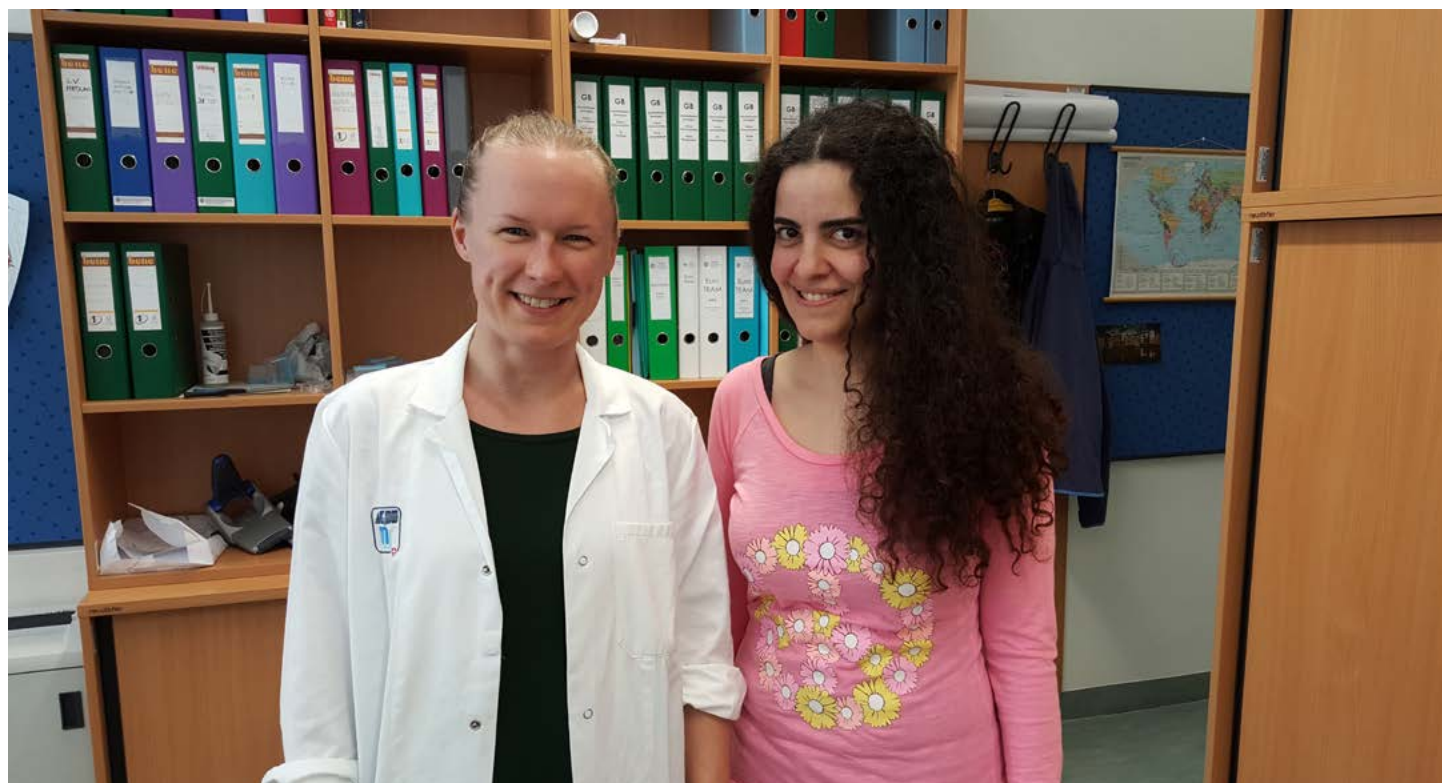
We plan to continue with the campaign next year, especially in the context of better recognition of patients with spondyloarthritis. There is room for improvement in the area of health promotion among patients and their relatives, patient management and the prevention of co-morbidities.



Milena Pavic Nikolic

We want to contribute maximally and, together with other EULAR members, achieve the goal of providing patients with professional and quality care.

Learning from each other



Maria Bergström (left) and one of her hosts, Maisa Omara, at the Medical University of Vienna's Centre for Medical Statistics, Informatics and Intelligent Systems

Maria Bergström, MSc OT, PhD Student, from the Division of Occupational Therapy at Linköping University, Sweden made an educational visit to the Medical University of Vienna's Centre for Medical Statistics, Informatics and Intelligent Systems in April 2018. Here she reports her learnings and shares observations on differences in practice between the two countries

My visit took place over 2.5 days in Vienna in three locations: at the Medical University, the General Hospital and at a rehabilitation centre in Baden, a short train ride outside of Vienna. My supervisor during the visit was Dr. Prof. Tanja Stamm of the Medical University of Vienna, Austria.

During my first afternoon I met with my hosts and supervisor to plan the coming days in more detail. At this point, I had the opportunity to have the International Classification of Functioning, Disability and Health (ICF) discussion that was one of my objectives for the visit. I sat down with MSc Gabriele Gäbler and we talked about how the ICF could be dealt with in research and also in practice. I presented parts of my PhD project where I have performed mapping according to the ICF, and received nice feedback on how the classification can be used to highlight activities, the way I had used it in a results section in my project. I felt encouraged in my work and inspired to further develop the mapping I have performed, and use it in different settings, such as presentations or conferences.

Providing a better service

Day 2 was spent with MSc Maisa Omara

at Peterhof Rehabilitation Centre in Baden. There, I was given a tour of the centre, and visited the physical and physiotherapists, and occupational therapists (OTs). I saw the different forms of therapies available at the centre, such as water from the local hot springs, electrotherapy, water gymnastics and several types of massage.

Since the occupational therapy rooms interested me especially, I was very happy to see that aids and devices, such as orthoses, sand and paraffin, were available for the patients. There were opportunities for patients to perform kitchen activities, although I observed that kitchens developed in Sweden for rehabilitative activities are more used and more advanced. The OTs at this rehabilitation centre had equipment for making different types of orthoses for the patients. In Sweden the OTs mostly have the possibility to manufacture from harder material for the

patient. The OTs at Peterhof had a great amount of leather to use and a “work station” to make softer orthoses for the patient at the centre. This to me was a very nice service for the patients, as their stay at the centre could take on an even more holistic approach.

This I feel is something I will take with me, as the greater number of different aids and equipment we can offer directly at the centre/ clinic, the better service we can provide. There is a difference when it comes to devices, however, regarding the regulations of payment for recommended items. At Peterhof (as in Austria in general), patients have to buy recommended devices themselves. A special service at Peterhof enabled patients to purchase devices from the OTs. In Sweden, depending on the location, many devices are prescribed and the patient does not pay.

Research focus

A reason for visiting Peterhof was also to see the register study in process. MSc Maisa Omara and I had very good discussions about how research is performed and prioritised in our different countries. I feel that the focus in Sweden can be wide – different studies can have purposes of testing aspects of medications and rehabilitation, but can also to look for indicators of certain symptoms or situations, thus also taking the aspect of prevention into account. In Austria, the focus today is mostly on treatment – the research area around prevention is not prioritised. Therefore, I found the study in process to be very interesting and important as it aims towards prevention in the future. Since I have not yet come across a register study in my PhD project, I learned a lot from this afternoon discussing the process with its possibilities and obstacles.

On Day 3 I had the opportunity to spend a few hours at the outpatient clinic with the OTs as they saw patients with different rheumatic diagnoses. This I found very interesting and I had a good insight into the daily practice and, at the same time, I had the opportunity to reflect upon our different ways of meeting patients in Sweden and Austria. Like the day before, I noticed several differences. The one which struck me the most was that patients only came to the OTs for assessments. In Sweden, we assess also, but interventions and follow-ups are a natural way to continue the process. At this outpatient clinic there was a desire to discuss daily life with the patients, but

time and resources were limited. In my opinion, a team of different professions performing interventions using a holistic approach is a good way to meet and treat patients. But to be restricted due to economy and time is naturally not an optimal situation.

Developing skills

My last stop during the visit was a journal club with other PhD students at the department. During this session, different professions were represented, such as occupational therapists, physicians, nurses and physiotherapists. It focused on a presentation with discussion afterwards. This was a different approach to the seminars we have at my department at Linköping University. The opportunities for PhD students to meet is very different from university to university, but I enjoyed this approach very much. At Linköping we mostly handle manuscripts, which can take the shape of a more interrogational format,

where a PhD student defends their manuscript. During the seminar in Vienna – which started with a presentation – I found it easier to have an open general discussion about the topic. To me, discussions are an important part of the learning process. Practicing the skill of presenting your work is also important and I sometimes feel that it should be offered more frequently at my own department. To have a seminar circling around a presentation and a general discussion is something I feel we should try to implement more often.

I feel that I gained a lot of knowledge during this visit regarding the different ways we have contact with patients in Austria and in Sweden. Additionally, I gained new ideas about the research environment offered at my department, as well as research topics and the processes during studies.

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Maria was impressed with the services offered by the therapy department at Peterhof Rehabilitation Centre in Baden

Will Gregory, Advanced MSK Practitioner (Rheumatology) from Salford Royal NHS Foundation Trust in the UK, also made an educational visit in April 2018. He reports on his three days with the myositis rehabilitation team at the Karolinska Institute, Stockholm



Myositis is a rare condition affecting the muscles, and research into rehabilitation techniques to benefit people with myositis is even rarer. Working at a UK specialist centre for myositis, I have recently been involved in seeing these patients for assessment, measurement and rehabilitation. I soon realised that our practices here in Salford could be enhanced by learning from the world-renowned myositis service at Sweden's Karolinska Institute.

Description of the experiences

In discussions with Dr. Helene Alexanderson we identified three days as the optimal visit period.

Monday morning: We started with a tour of the department followed by informal discussions on the research base in myositis rehabilitation, the database I had collected thus far in Salford and the service at the Karolinska. The clinical lead for the service, Dr. Ingrid Lundberg, and her second in command, Dr. Mariam Dastmalchi, joined us for lunch and it was nice to see how highly Helene was regarded by the medics and the easy relationships between different professions in the myositis team.

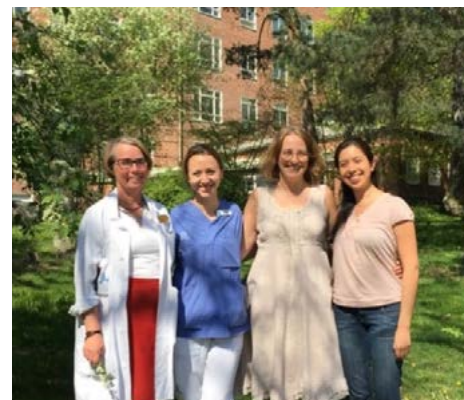
Monday afternoon: I had some time with Kristof Andreasson, a PhD candidate, and was fortunate to get hands-on (or at least leg-on)

experience of the testing protocol for the latest RCT the team are undertaking. I performed the 13 repetition muscle fatigue testing (for quadriceps) with the Biodex machine – this active learning really appeals to me. Later in the afternoon I discussed with Helene the paediatric / juvenile services in each of our countries and our shared acquaintance Sue Maillard at Great Ormond Street Hospital.

Tuesday morning: We looked at the exercise protocol for inclusion body myositis (IBM) which Helene has taken from the research studies in Australia (having found that her own home exercise protocol did not have as good effects as theirs in IBM). We then looked at the practical application of the FI-2 measure, with me acting as a model for her normative data collection project. The 33 minutes of muscle fatigue testing were challenging for me to perform and made me more aware of how good a test of muscle fatigue this outcome measure really is – as a fit(ish) individual I was both a little disappointed, but equally reassured to see I did not achieve 100% for the measures. We then had a patient attend for a dermatomyositis annual review – I saw the FI-2 in its clinical application as well as the Grippit machine.

Tuesday afternoon: We had a three-hour long myositis exercise group. I was impressed that an all-afternoon exercise class was filled despite myositis being a rare condition. I enjoyed seeing the group in action and there was a mix of newer and more established patients. It was great to see the role that Helene had – acting as a go between for the patients wanting to interact with the rheumatologist, their local physios and local GPs.

Wednesday morning: The day started with the weekly myositis research meeting, this included two patient representatives. All members were kind enough to conduct the meeting in English for me. There is a large cohort of PhD candidates and a broad range of areas are being researched. The patient representatives stayed on to discuss their experiences of rehabilitation at the hospital and in their local exercise services with me. I then returned to the physiotherapy gym and saw the application of the Astrand cycle ergometer protocol for an annual review patient. The visit finished with chatting through with Helene the UK services, my plans for implementing some changes on getting back to the UK and potential future research projects – both to look at myself and as a collaborative international project.



The Karolinska team

Summary of the planned learning outcomes

My learning objectives had been agreed before I began the visit. The key learning points that addressed these were:

*To discuss the FI-2 outcome measure and observe it being applied (Di, De, O, Q, L *)*

See Tuesday morning summary above. I have learnt how the outcome measure was developed and am aware of its testing for specificity, sensitivity and repeated use. I have seen it being applied four times, including performing it as the subject myself.

To sit in on the physiotherapist-led myositis clinic with yearly check-up appointments (De, Di, O, Q)*

See Tuesday morning summary above. We discussed the need for these review appointments and their role in the ongoing management of these patients. I have seen this appointment and had chance to discuss it with both Helene and the patient.

To observe gym exercise groups for patients with myositis (Di, De, O, Q)*

See Tuesday afternoon summary above. We discussed the why and I observed 3 separate classes. I have learnt how and why these sessions are run; and had a chance to consider how we might best replicate this on the UK.

To observe the application of a Biodex protocol for assessment of muscle strength and endurance for myositis. To meet the PhD student in this project (De, Di, O, Q)*

See Monday afternoon summary above. I saw this protocol (and underwent it as the participant in this demonstration). I had a chance to discuss



the protocol and have since reflected on how we could use our own Biodex machine more often for our myositis cohort in Salford.

**Di = Discussion, De = Demonstration, O = Observation, Q = Questioning, L = Literature*

Influencing practice back home

- (1) We need to use a Borg scale to ensure our patients are exercising at an optimal level when we are working with them in the gym.
- (2) It is permitted to use the FI-2 in its individual parts. That means we could test just one component of it and still use this data to monitor patients' muscle strength / fatigue.
- (3) Use of the dynamometer has been shown in previous research by Helene to be inconsistent for, for example, quads testing. Therefore, it is worth collating my data sooner to see if it concurs and, if so, then to stop recording this data in this way.
- (4) Using the Biodex is a lot easier than I had imagined and gives good data for strength and muscle fatigue.
- (5) Group-based exercise treatment does look a workable application for this group of patients.
- (6) Inputting data into – and accessing data out of – the Myonet database is essential.

Implementing change

As a result of my visit and the insight it has given me, I have developed a brief plan for implementing changes back in the UK. I plan to do the following:

- (1) Re-request access to the drive where the Myonet database is held and retrospectively input some data for patients I have seen.
- (2) Print out and laminate a Borg scale for use in the gym and consider trial of this in one of the gym groups.
- (3) Trial the Biodex machine, following the Karolinska protocol, initially on the team (out band 2s) to gain proficiency and then on a number of myositis volunteers. Consider how this could be used in (a) the clinical environment and (b) research.

- (4) Produce SRFT-branded / document control approved HEP booklets for (a) IBM and (b) IIM.
- (5) Re-establish writing to all IIM clinic patients 1-2 weeks prior to their HC appointment to ask them to come 20-30mins early for physiotherapy assessment, review and treatment.
- (6) Distribute my learning experiences amongst other myositis-interested physios – at the BSR conference and through social media.
- (7) Maintain a link with Helene / the team at the Karolinska.
- (8) Share this plan with the myositis team in Salford as an accountability tool for myself and as an aid in driving the service forwards.

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Apply for a grant

EULAR awards up to 10 bursaries per year for educational visits. They are to enable HPRs to visit colleagues to improve the standard of research and care in allied health professions and to foster collaboration across clinical units in Europe.

The amount of each bursary is between EUR 750 and 1,500. Recipients are required to submit a short report to the EULAR Secretariat after their stay, focusing on the results that have been achieved. Information about how to apply can be found on the EULAR website at https://esor.eular.org/theme/lc_eular/layout/enrol.php?id=28

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

EULAR HPR Study Group reports

The EULAR HPR Study Groups (SGs) met face-to-face at the EULAR 2018 Annual European Congress of Rheumatology in Amsterdam. Here, the Study Group leaders provide their feedback

EULAR Foot and Ankle Study Group

By Gabriel Gijon Nogueron and Robert Field, Study Group Co-leaders



Gabriel Gijon Nogueron

In recent months there have been some changes within the EULAR Foot and Ankle Study Group (SG). One of those is the inclusion, from last March, of Robert Field as the new co-convenor to help share the group's workload. Our member from PARE, Elsa Frazão Mateus, has had to leave the SG to dedicate more time to PARE activities and we would like to wish her good luck in her new projects. The group's membership has increased with three new members from PARE and two health professionals in rheumatology (HPR), bringing the total membership to 33 representing 12 countries.

The SG has proposed an HPR Session for the 2019 EULAR Congress in Madrid relating to "Footwear Interventions for Arthritis Foot Pain". Our member Tiziana Nava is working on a proposal for the 2020 EULAR Congress in Frankfurt.



Robert Field

One of the objectives of this Study Group is to prepare a EULAR HPR grant application to support further investigations into the foot and ankle problems in patients with rheumatic and musculoskeletal disease (RMDs) within the EULAR member countries.

The group continues to meet four times per year, with a face-to-face meeting at the EULAR Congress and the other meetings happening online. Full details will be circulated to those already on the group's email list, but anyone who would like to join the group or would like further information should contact us as the group's co-convenors at gagijon@uma.es (Dr. Gabriel Gijon-Nogueron) or rfield@nhs.net (Robert Field).



Members of the Foot & Ankle Study Group at their meeting

EULAR Physical Activity and Exercise Therapy Study Group



Rikke Helene Moe

By Rikke Helene Moe, Study Group Lead, and co-leaders Li Alemo Munters and Thijs Swinnen.

25 members of the group squeezed into a small meeting room during the Friday evening at the Congress in Amsterdam – just after the project session where our new 2018 EULAR Recommendations for Physical Activity in People with Inflammatory Arthritis and Osteoarthritis were presented. The group was very happy with the work presented, and the enthusiasm and interest shown by the EULAR participants. Several members of the Study Group took part in the Task Force, and we discussed how to take the recommendations further. The Study Group will, in the next year, initiate implementation projects through a subset of members, and this will be discussed with all via our LinkedIn group page.

Interesting new projects were presented, and group members were recruited to join different initiatives. One of the projects was presented by Ricardo Ferreira about an HPR research grant-funded project on a web-based collaboration to promote physical activity and exercise in patients with systemic sclerosis. The need for recommendations for physical activity and exercise in connective tissue diseases was also discussed and will be followed-up further in coming years.

The new EULAR Strategy was briefly presented, followed by a discussion on its potential consequences for our group's priorities. We are so lucky to have such a knowledgeable, enthusiastic and lively group who are ready to work. We will collaborate closely on implementation ideas, on the web-based project and on new congress proposals over coming months.



EULAR Nurses' Study Groups – Clinical and REST

By Jenny de la Torre, Clinical Leader and Yvonne van Eijk-Hustings, REST Leader

This year the nurses' Clinical and REST Study Group meetings were planned simultaneously. Therefore, all nurses were invited into the clinical meeting chaired by Jenny de la Torre. The meeting consisted of three presentations and a discussion on future meetings.

The 2018 update of the EULAR Recommendations for the role of the nurse were presented. In total, the update resulted in three overarching principles and eight recommendations, with an increased level of evidence and a high level of agreement among the task force members. The update was also presented during a poster tour on the Friday, and publication is expected by the end of the year.

Furthermore, an idea for exploring the content of nurse consultations in Portugal was discussed. It might be worthwhile exploring the content in more



Jenny de la Torre



Yvonne van Eijk-Hustings

countries. There was an interesting discussion on the relevance of taking context into account: educational level of nurses, legal regulations regarding responsibilities and independence for example. The importance of studying the cost-effectiveness of nursing interventions was discussed – comparing cost effectiveness of basic and advanced nursing in the care of people with inflammatory arthritis taking into account clinical,

work, social and economic variables.

Finally, a discussion on future meetings was held. In 2012, applications for two Study Groups were submitted: the nurses Clinical SG and the nurses SG for Research and Strategy (REST). Both applications were approved by EULAR. However, since then, there has been an ongoing discussion with regard to the groups:

1. EULAR does not want profession-specific SGs
2. The distinction between the groups is unclear, resulting in confusion for (potential) participants.

As working groups within REST are successful in publishing on different relevant health professional topics, resulting in several publications, both SG leaders have proposed that EULAR closes the nurses' Clinical SG and that both study groups merge into REST.

EULAR Study Group on Patient Education (STOPE)

By Mwidimi Ngosi, Study Group Leader



This was the third STOPE meeting, attended by 17 members from 12 countries with five professions represented. Apologies were received from seven members. There were other HPR SG meetings running concurrently, thus affecting the attendance to our meeting which was chaired by Dr. Mwidimi Ndosi (UK) with Dr. Andrea Marques (Portugal) taking notes.

Notable achievements over the last three years include the translation of the patient education

recommendations into 11 languages, with some countries having translated the lay version and published their translations. Also, a survey was conducted in Switzerland two years ago to assess acceptance of recommendations.

The priority for the coming year is to conduct a Europe-wide survey to assess acceptability and applicability of the recommendations. The survey will be managed by the University of the West of England (UWE) Bristol, UK. At

the meeting, STOPE members were invited to comment on the draft survey items, which contained both rating scales and open-ended questions. It was noted that analysing open-ended questions would be time-consuming but necessary for identifying facilitators and barriers to implementation.

It was agreed that country champions will translate the survey items into their respective languages and send them to me at UWE in Bristol and I will also construct the online survey. After launching the survey, two months will be allowed for data collection, and country champions will be asked to translate the open-ended responses. I will ensure that the project is compliant with the new EU General Data Protection Regulation. The desired outcome is to disseminate and promote implementation of the recommendations for patient education across Europe.

Everyone was thanked for their contribution towards achieving STOPE objectives.



Mwidimi Ndosi

Meet the national health professional delegates on EULAR's HPR Standing Committee

There are 25 formally ratified EULAR HPR organisations represented by their presidents or other nominated officials on the EULAR Standing Committee of Health Professionals in Rheumatology.

The national HPR delegates contribute to shaping health professional activities within EULAR.

The Committee, headed by Chair Rikke Helene Moe, Past Chair Annette de Thurah and EULAR Vice President representing health professionals in rheumatology Tanja Stamm, discusses ongoing projects and new proposals for the EULAR Executive Committee, initiates the health professional programme for the EULAR Annual European Congress of Rheumatology, and supports and reviews HPR membership applications.

Each year the Committee holds its annual meetings at the EULAR Congress. It has sub-committees and can also include other invited experts.

Rikke Helene Moe: rikmoe@gmail.com

Tanja Stamm: tanja.stamm@meduniwien.ac.at

Annette de Thurah: annethur@rm.dk



Austria: Simone Luschin
The president of the Österreichische Gesellschaft für rheumatologische Gesundheitsberufe (ÖGRG)



Belgium: Thijs Swinnen
The president of the Belgian Health Professionals in Rheumatology



Croatia: Branka Rimac
The president of LABUD, the Croatian Society of Health Professionals in Rheumatology



Cyprus: Costas Ioulianos
The president of the Cosmorama+



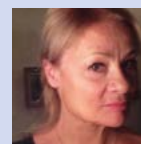
Czech Republic: Hana Šmucrová
The president of the Czech Association of Health Professionals in Rheumatology



Denmark: Janni Lisander Larsen
The president of the Danish Interdisciplinary Forum (DIRF)



Finland: Sirkuu Ala-Peijari
The president of the MSD-professionals of Finland, SUOMEN TULESAMMATTILAISET R.Y.



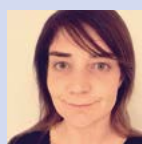
France: Françoise Alliot-Launois
The president of the French society of health professionals in rheumatology, Pro Rhumato



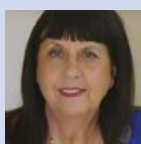
Germany: Ulrike Erstling
The president of the German Fachverband Rheumatologische Fachassistenten e. V.



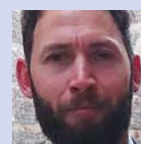
Hungary: Andrea Domján
The president of the Hungarian Association of Rheumatology Health Professionals



Ireland: Patricia Fitzgerald
The president of the Irish Rheumatology Health Professionals in Rheumatology



Israel: Naomi Schultz
The president of the Israeli Rheumatology Multi-Disciplinary Forum



Italy: David Biscotini
The president of FOR-RheUMA, the Italian Society of Health Professionals in Rheumatology



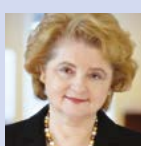
Malta: Dr. Alfred Gatt
The president of the Maltese Health Professionals in Rheumatology



Netherlands: Wilfred F Peter
The president of the Netherlands Health Professionals in Rheumatology



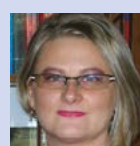
Norway: Camilla Fongen
The president of the Norwegian Interdisciplinary Organisation in Rheumatology (NIOR)



Poland: Prof. Anna Kurylszyn-Moskal
The president of the Polish Society of Health Professionals in Rheumatology



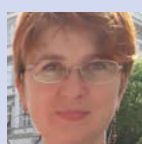
Portugal: Lurdes Barbosa
The president of the Portuguese Association of Health Professionals in Rheumatology (APPSReuma)



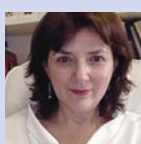
Romania: Cristina Ioan
The president of the Romanian Society of Medical Partners for Rheumatology (RSMRP)



Serbia: Svetlana Zekovic
The president of the Serbian Association of Health Professionals in Rheumatology (SAHPR)



Slovenia: Milena Pavic Nikolic
The president of the Slovenian Health Professionals in Rheumatology



Spain: Milena Gobbo Montoya
The president of the Spanish OPENREUMA



Sweden: Li Alema Munter
The president of the Swedish Rheumatology Forum, SveReFo



Switzerland: Agnes Kocher
The president of Health Professionals in Rheumatology Switzerland (hpr)



UK: Caroline Flurey
The president of the British Health Professionals in Rheumatology (BHPH)

For contact details of all the member organisations and nominated EULAR liaison personnel, please visit the EULAR website to find the most up-to date information.
www.eular.org/health_professionals_membership.cfm

Editorial office

Publisher: EULAR Standing Committee of Health Professionals in Rheumatology – Seestrasse 240, CH-8802 Kilchberg, Switzerland

Editor: Kate Betteridge, kate@katebetteridge.me.uk

Layout design: Heikki Luukkonen, HL-Mark, Finland

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