



Issue 3 • 2018 Spring

# HPR News

Newsletter of the Health Professionals in Rheumatology

# eular

fighting rheumatic & musculoskeletal diseases together

## Don't Delay, Connect Today gains momentum



The pillars of EULAR came together in Brussels to launch the Belgium Don't Delay, Connect Today campaign

*Don't Delay, Connect Today* is a EULAR campaign that, for the first time, engages all three EULAR pillars: health professional associations, patient organisations (PARE) and scientific communities. It aims to raise awareness of the importance of early diagnosis in preventing further damage to those living with rheumatic and musculoskeletal diseases (RMDs) and to encourage timely access to evidence-based treatment.

EULAR launched a campaign call in late 2017 to all areas of the EULAR network, offering 12 bursaries, each worth Euros 5,000, to member organisations wishing to execute the EULAR campaign at their national level. Following applications from across Europe, 12 countries were selected.

A member of the EULAR Campaign Task Force, speaking on behalf of Marios Kouloumas, EULAR Campaign Task Force Lead, said: "The grants will provide the member organisations with financial support to bring the *Don't Delay, Connect Today* message to life in their 12 countries in 2018."

### 12 countries, 12 bursaries

The first campaign event of the year was the Belgian national launch hosted by ReumaNet vzw, the EULAR national patient member organisation, on 15 February in the Belgian Federal Parliament in Brussels. The event included keynote presentations from the EULAR Executive and an exhibition with real-life plaster hand and foot prints showing the visual difference of early versus late diagnosis.

EULAR President, Prof. Johannes Bijlsma explained to policy-makers, members of parliament and members of national media that the campaign would travel to different parts of the country to promote the need for early diagnosis and access to care for those with RMD symptoms.

A further 11 countries will implement the campaign with dedicated events in 2018. The countries are Cyprus, Finland, Malta, the Netherlands, Poland, Romania, Serbia, Slovenia, Sweden, the United Kingdom, as well as the University of Glasgow.

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HPR News

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## > Don't Delay, Connect Today gains momentum



EULAR's Marios Kouloumas and Prof. Ruxandra Ionescu help launch the Romanian campaign

"Don't Delay, Connect Today" continues to grow across Europe and has also seen an echo in countries as far afield as India and Bangladesh. Looking to the future, the EULAR Campaign in 2018 will explore opportunities to spread the word to society at large, particularly with the upcoming World Arthritis Day events on 12 October," said a member of the EULAR Campaign Task Force.

### Working with one voice

April saw Romania launch the campaign with involvement from the three Romanian EULAR member organisations – Romanian League against Rheumatism, Romanian Society for Rheumatology and Romanian Association of Medical Partners for Rheumatology. Prof. Tanja Stamm, Vice President EULAR, representing health professionals in rheumatology (HPRs) spoke at the event about "The role of health professionals in early diagnosis and timely treatment" on behalf of the EULAR HPRs.

"It was an honour to support the Romanian Association of Medical Partners for Rheumatology to help them launch this exceptionally important campaign," said Prof. Stamm. "It is so important that national EULAR member organisations from all three pillars promote the campaign nationally, highlighting the issues key to their country. And it is essential that the pillars of EULAR work together to

speak with one loud voice."

The high-level events in Brussels and Bucharest follow another national campaign launch at the Portuguese parliament in Lisbon, Portugal in February 2017.

After the launch in Bucharest, a series of public events have also taken place in Romania, following a co-ordinated media plan. An educational event was organised which saw educational flyers and other educational materials distributed in shopping centres, metro stations and other crowded places.

### Take action!

Everyone, everywhere can support the EULAR Campaign. One way HPRs can assist is by following @eular\_org and @ArthritisDay

on Twitter, @worldarthritisdaily on Facebook and worldarthritisdaily on Instagram. Use the campaign hashtag #ConnectToday in each and every social media post you compose. Engage with the social media posts – your likes, comments and shares all build the campaign's reach and impressions throughout the world.

To gain direct information on the EULAR campaign, download the HPR dedicated toolkit available on [www.worldarthritisdaily.org](http://www.worldarthritisdaily.org) and also on the campaign page on the EULAR website at [www.eular.org/what\\_we\\_do\\_dont\\_delay\\_connect\\_today.cfm](http://www.eular.org/what_we_do_dont_delay_connect_today.cfm)



*Don't Delay, Connect Today* was developed to address society at large – to motivate people to recognise possible health warning signs that their bodies may be experiencing and to take action immediately by contacting their healthcare provider.

Will you #ConnectToday?



EULAR President Prof. Johannes Bijlsma is interviewed by Belgian press at the Brussels launch

## Get in touch

Welcome to your spring issue of EULAR HPR News. It has a focus on young researchers and is packed full of articles about exciting projects and new developments from EULAR and national HPR organisations.

I hope to see many of you at the EULAR Annual European Congress of Rheumatology in Amsterdam. Please pop by the HPR booth in the EULAR Village to say hello and network with colleagues. You will be very welcome.

If you are interested in attending an HPR Study Group meeting at the congress, you can find out when they are happening on page 18, while an 'at-a-glance' programme of the HPR congress sessions is available on page 19.

Enjoy your read.

If you have any ideas, don't keep them to yourself. Email me at [kate@katebetteridge.me.uk](mailto:kate@katebetteridge.me.uk)

Kate Betteridge  
Editor, EULAR HPR News

## Do you have good news for the newsletter?

**Prescribe the newsletter free of charge to colleagues at [www.eular.org/health\\_professionals.cfm](http://www.eular.org/health_professionals.cfm)**

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.



# EULAR HPR research strategy 2018–23: Improving quality of life for people with RMDs

The EULAR Standing Committee of Health Professionals in Rheumatology sets out its new research strategy for the next five years

Macroeconomic trends, changing demography and the development and increasing use of technology will shape the health care system of the future. The need to prevent and manage rheumatic and musculoskeletal diseases (RMDs) and their impact will increase and evolve. This emphasises the importance of optimised evidence-based care, innovation and seamless collaboration between the healthcare system and other stakeholders.

EULAR Health Professionals in Rheumatology (HPR) will conduct research that substantially contributes to the knowledge and evidence base to enhance the quality of life for people with RMDs and meet evolving circumstances. Accessibility, equity, organisation of healthcare services, outcomes and policy improvements relevant to people with RMDs will represent important future areas of research.

Therefore, the future HPR research projects should be aimed at:

- maintaining and improving individuals' everyday life and participation in functional activities and society
- enhancing individuals' ability to self-manage RMDs
- supporting individuals to stay in – or return to – work and education
- reducing inequality and inequity in healthcare for people with RMDs.



The EULAR Study Group for REsearch and STrategy. Yvonne van Eijk-Hustings is seated front row, 2nd from right

## REST: Working across nations

Yvonne van Eijk-Hustings and Bianca Bech provide an update on recent developments with EULAR's nurses study group for research and strategy

The EULAR nurses Study Group for REsearch and STrategy (REST) aims to provide a platform for collaboration and international research. Our network is dynamic and comprises people from many European countries, the USA, Australia, New-Zealand and Asian countries, such as Japan and Hong Kong.

Several project groups participate in REST, with the number and kind of groups fluctuating. Work has resulted in international peer reviewed publications on the role of nurses in cardiovascular risk, readability of informed consent materials, and agreement with – and feasibility of – the EULAR

Recommendations for the role of the nurse in Japan (Primdahl et al. 2016, Hamnes et al. 2016, Fusama et al. 2016).

There are two current working groups.

- The rheumatology nursing sensitive outcomes task force (RNOT: UK, Ireland, USA, the Netherlands), co-ordinated by Patricia Minnock and Mwidimi Ndosi, which aims to develop a core set of rheumatology nursing sensitive outcomes. A systematic literature review that supports this work has been published (Minnock et al. 2018).
- The European Qualitative

research collaboration on Patient-preferred outcomes in Early RA (EQPERA: Belgium, Sweden, the Netherlands) co-ordinated by Kristien van der Elst (Belgium), which currently performs a longitudinal study on preferred health and treatment outcomes. The study protocol, the first on a longitudinal qualitative study, will be submitted soon.

*“People can benefit from the expertise of others”*

Besides the above, people can connect in order to benefit from the expertise of others in

designing and performing studies in their countries. For example, a study on nurse-led care in Germany will be supported by expertise from Denmark and the United Kingdom.

Moreover, we intend to start a joint project: exploring changes in the development of extended roles in Europe by repeating (a part of) the survey on health professional roles which was presented at the EULAR Congress in London 2011. However, the context of nursing care still differs widely across Europe. We will need detailed descriptions of this to fully understand data from the survey.



Bianca Bech

Currently, the EULAR Recommendations for nurses are being updated and we expect that the review performed for this update will provide input for the role descriptions. We will continue working on this project as soon as the updated recommendations are published.

# Edgar Stene Prize 2018 celebrates personal champions



Magdalena Misuno from Gdańsk in Poland has won the 2018 Edgar Stene Prize competition. 37-year-old Magdalena, who has systemic lupus erythematosus, was voted the best essayist writing on the theme of "My personal champion – supporting my everyday life with a rheumatic and musculoskeletal disease (RMD)".

"I wanted to use my essay to thank the people who support me in my everyday life with an RMD," said Magdalena. "Secondly, I wanted to communicate to others that our present life, and our attitude towards ourselves and the world that surrounds us, is really up to us alone."

*"The competition invites entrants to write about personal experiences"*

Magdalena will be awarded her prize at the Annual European Congress of Rheumatology in Amsterdam in June. She will present her essay in the PARE Abstract Session on Friday 15 June in the PARE Room at 10.15am. This year's 2<sup>nd</sup> prize winner is Per Clausen from Denmark, with 3<sup>rd</sup> place being awarded to Maiken Brathe from Germany.

The competition invites entrants to write about their personal experiences of living with an RMD. A 2018 Edgar Stene Prize booklet with an anthology of entries will be ready for the EULAR Congress and available at the HPR Booth in the EULAR Village.

It can also be downloaded from the EULAR website ([www.eular.org/pare\\_stene\\_prize.cfm](http://www.eular.org/pare_stene_prize.cfm)) after the congress.



## From the Chair

# Digital health and the role of HPRs

From Annette de Thurah, Chair of the EULAR Standing Committee of Health Professionals in Rheumatology



In a recent report, the International Telecommunication Union (ITU) noted a tremendous change in global internet use – from 400 million users in 2000 to 3.5 billion users by the end of 2016. This now corresponds to 53% of the global population. Restricted resources and increasing demand means that the technological advancements of the next decade may cause greater shifts than have previously been navigated.

This is also reflected in the many abstracts submitted to the chair of the EULAR Standing Committee of Health Professionals in Rheumatology. With each passing year, we receive more and more abstracts dealing with digital health.

*"We will witness an increase in telemedicine consultations"*

Thus, it must be expected that, in years to come, we will witness an increase in health professional consultations performed as telemedicine consultations. This applies, for example, to telemedicine disease monitoring<sup>1</sup>, telemedicine patient education<sup>2</sup>, or to the use of a digital intervention to promote physical activity among

patients with rheumatic diseases<sup>3</sup>.

Further, future wearable devices will potentially alter long-standing assessment tools and practices for health professionals within rheumatology (HPRs). People are already collecting a myriad of electronic data such as heart rate, blood pressure, weight, activity level and so on. In the future, health professionals may serve as primary investigators of technological connection and data transfer between patients and clinicians.

*"Future wearable devices may alter long-standing practices"*

Digitalisation has many advantages, and the march of events cannot be stopped. However, when we digitalise interventions we also need to redesign patient education and self-management strategies to meet the new demands.

Access to technology will have significant influence on the determinants of health for future populations, and HPRs must be prepared to assess and support patients at risk of disparity due to technical inequity. Patients will also present with great differences in digital literacy and even computer skills. HPRs should take the lead in providing the needed patient education and research within this area.

Let's hope we will find plenty of abstracts within this area in the future. We need them!

1. Thurah A, et al. A Tele-health Follow-up Strategy for Tight Control of Disease Activity in Rheumatoid Arthritis: Results of the Non-inferiority Randomised Controlled Trial (the TeRA study). 2017.

2. Cicciello S, et al. Improving treatment with methotrexate in rheumatoid arthritis: development of a multimedia patient education program and the MIRA, a new instrument to evaluate methotrexate-related knowledge. 2014;43(4):437-446.

3. Rovenas A, et al. Development of a web-based and mobile app to support physical activity in individuals with rheumatoid arthritis: results from the second step of a co-design process. 2015;4(1):e22.



# Old joints and new perspectives versus young joints and new challenges

**From Tanja Stamm, EULAR Vice President representing Health Professionals in Rheumatology**

"Old joints and new perspectives" was the title of an invited speaker session at a EULAR Congress some time ago. In this session, new and innovative approaches for knee osteoarthritis were discussed. The future, therefore, lies in the hands of young people. Our latest newsletter is dedicated to young people in rheumatology – young health professional clinicians and researchers, but also young patients and rheumatologists.

EULAR already offers some support for young people, including health professionals in rheumatology (HPRs) but also, specifically, for young patients and young rheumatologists. Some of these are described in our newsletter. However, despite these ongoing initiatives, I am convinced that young HPRs – both clinicians and researchers – need even more support and attention in the future. If we do not invest in our youth, in our successors, we will miss opportunities for development. Young people, for example, have the privilege challenging tradition which is extremely important in "tradition-rich" areas such as medicine and research.

The future, however, is not only bright as we will have to face other challenges of which we do not yet know. Thus, we will need our "older" and more experienced people for advice to be able to master these new and unexpected challenges. Young people will ideally collaborate and work together with more experienced "older" experts and will ask them for advice.

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*"We will have to face other challenges"*

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Young people also need to collaborate across all three pillars of EULAR: patients, rheumatologists and HPRs. Young patients had a specifically targeted workshop at the 21st PARE conference held in February 2018 in Brussels which



Tanja Stamm (right) in a panel discussion on early diagnosis and prevention at the EULAR Annual Conference of PARE

was dedicated solely to young patients (and not to the activities of young HPRs). Health professionals moderated a different workshop at this conference on the co-operation of PARE and health professionals across all ages. Patients not only benefit on an individual basis from the interventions of HPRs, but also at an organisational level where patient organisations work closely with health professionals.

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*"We hardly implement this knowledge in our daily life"*

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Exactly this collaboration was the topic of a workshop at the annual PARE conference. In our workshop, Li Allemo Munters, Els van den Ende and I focused on behavioural changes and what can be done by health professionals and patient organisations together. Despite that we all (or most of us) know what is healthy, we hardly implement all this knowledge in our daily life and change our behaviour. We stop exercising, buy and eat unhealthy food, continue smoking and conduct stressful jobs. Health professionals can offer strategies to help. In addition, national PARE organisations may be ideal partners for starting campaigns and large-scale activities at the organisational level that can reach more people, more regularly as we know that motivation for a healthy life style decreases over time.

The results of a survey carried out by EULAR among HPRs and PARE organisations showed that 36% of all PARE organisations have already run a healthy lifestyle or health promotion activity or campaign involving health professionals in rheumatology. Furthermore, 50% of all PARE organisations are planning a healthy lifestyle or health promotion activity or campaign to help prevent or reduce damage from RMDs. The most commonly collaborated with HPRs are physiotherapists, specialist nurses, occupational therapists and psychologists.

A brilliant initiative could be to target such campaigns specifically to young people with RMDs, as well as young HPRs. Being commonly more open-minded might allow young people to come up with more innovative solutions to healthcare. These may include the new megatrends such digitalisation of health, the extensive use of social media and/or the development of social innovations.

Taken together, I am convinced that collaborations between young and "older" HPRs will drive the future of rheumatology care in Europe and will help us to successfully master future challenges. Furthermore, I think that the co-operation with PARE and Young PARE, and the – young and "older" – rheumatologists are essential aspects of our work.

# Global collaboration brings rewards

**Alyssa B. Dufour is a young health professional researcher based in the United States. She shares her thoughts with *HPR News* on opportunities available to young researchers and how she believes that collaborating internationally can bring benefits to everyone working in the rheumatology field**

I am an Assistant Scientist and Biostatistician at the Institute for Aging Research at Hebrew SeniorLife in Boston, Massachusetts and an Instructor in Medicine at Harvard Medical School in the United States. I have a PhD in biostatistics from Boston University and my statistical expertise focuses on longitudinal trajectory analysis of risk factors related to rheumatic disease.

I have been involved in the Association of Rheumatology Health Professionals (ARHP) since 2007, presenting research and running statistical methods workshops at the annual meetings, and volunteering within the college on various committees and working on other tasks.

Because research life is highly structured, outside of work I love to dance – especially salsa dancing. It is so much fun and helps bring a great balance to life.

**Of all the medical fields you could have chosen to specialise in, why did rheumatology appeal? What have been some of the specific challenges of this disease area?**

My journey to rheumatology was rather spontaneous. While I was working on my PhD, I was placed in a research assistantship with Dr. Marian Hannan. Dr. Hannan is a well-known epidemiologist who has made her career working in the field of rheumatology – most notably for her work on foot problems and mobility in older adults. As a PhD student, Dr. Hannan took me under her wing and provided me with her invaluable mentorship and the opportunity to work on projects within the foot study.

As work from the foot study evolved, we found a home for presenting our findings at the annual meetings of the American College of Rheumatology (ACR). I have since presented many abstracts from our work in the foot study at the ACR/ARHP annual meetings, published our work in *Arthritis Care & Research*, and I became involved as a volunteer in the college – most recently as the ARHP representative to the ACR Committee on Education and member of the ARHP Executive Committee.

As a biostatistician, my interest in the field of rheumatology has evolved over the years as I work to apply my biostatistics training and interest in longitudinal trajectory analysis to rheumatologic diseases.

**Working with different specialties can bring so many benefits. What does interdisciplinarity mean to you and what can be done to make it work well?**

As a biostatistician, I think, by definition, I am interdisciplinary. I have the opportunity to work on many different research projects with experts in many different fields, all of which relate back to rheumatology. Working with different specialties

gives us the opportunity to explore different areas of research that are of interest.

**Patients are a key partner in research – alongside rheumatologists and health professionals in rheumatology (HPRs). What do you see are the benefits of involving patients?**

The ultimate goal of all research that we do is to improve the lives of our patients. I think involving patients in our research, especially in the planning phases of research studies, can help us to tailor our studies and data collection to most effectively target symptoms and diseases that are most important to our patients.

**You work in Europe as well as North America. Please tell us a bit about the project, how you became involved?**

Through my involvement in the ARHP, I was lucky enough to meet Prof. Christina Opava who is a physiotherapist at the Karolinska Institutet in Stockholm, Sweden. In 2009, I was awarded the ARHP Graduate Student Recognition Award and,





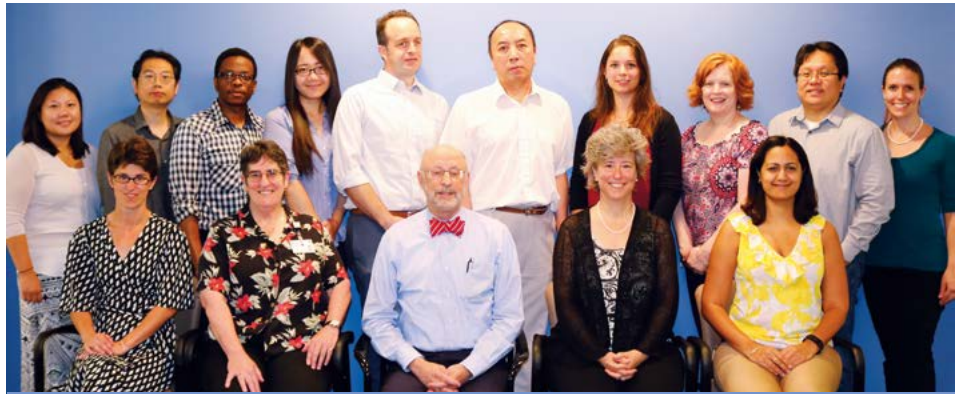
that same year, one of her students also received the award. Christina and my mentor, Dr. Hannan, knew each other well through the ARHP and she became very interested in me and my career. When I was finishing my PhD work, she reached out to me with the idea of having me come to the Karolinska Institutet to do a post-doctoral fellowship with her.

We ended up creating a very successful research collaboration where I visited the Karolinska multiple times for extended periods, working in her research group as a Visiting Professor. During the rest of the year, while in the US, I continued to collaborate on her project studying physical activity intervention in persons with rheumatoid arthritis (RA). We continue to maintain our collaboration working on papers and I act as a statistical consultant to her group. We hope to continue collaborating in the future on new research projects in rheumatology.

### How can EULAR and the ARHP support young health professionals keen to get more experience in research?

As we all know, obtaining funding to support our research is one of the most difficult obstacles that we face as researchers. Providing more grant opportunities to both young researchers and students while they are working on their degrees is key to helping health professionals succeed and obtain more experience.

The various awards that exist to assist young health professionals in attending the annual meetings, where they can present their work, obtain feedback from international colleagues and make connections with researchers who could become potential collaborators in the future, are incredibly helpful to young



My team at the Institute for Aging Research

researchers. Additionally, the ACR/EULAR exchange programme is another wonderful opportunity for young researchers.

I was lucky enough to be selected as the only health professional participant in 2017 and received support to attend the 2017 Annual European Congress of Rheumatology in Madrid and to attend a two-day workshop with other young health professionals in rheumatology and European researchers. I would personally advocate for including more PhD researchers in these exchange programmes or consider creating a separate programme for these non-clinicians as they could benefit greatly from this type of exposure.

### EULAR is very keen to encourage young researchers. What do you see as being the advantages for involving people early in their careers?

Being involved in EULAR early in their careers allows young researchers to become known to other eminent researchers in their field and, also, to meet other young researchers with similar interests. Networking with others can result in developing new research ideas, creating

collaborations or finding funding opportunities to help support their research. Getting to know people in your field, especially when you're just starting out, is immensely helpful in developing yourself into an independent, successful researcher.

### What would you advise to “really young” health professionals in rheumatology at the beginning of their careers?

Find a good mentor.

A mentor who can support you in your academic pursuits, career goals and personal life can greatly help form your career. One of the things I am most grateful for in my career so far is the mentorship, guidance

and support from Dr. Marian Hannan. Without the opportunities that were provided to me by Dr. Hannan, I would never have found my place as a biostatistician in the field of rheumatology.



Alyssa B. Dufour

### What are you looking forward to in the world of rheumatology research – both directly in your work and looking at the bigger picture?

I am most looking forward to watching our work translate into real interventions and changes in clinical practice to help rheumatology patients. A lot of the work we do can sometimes feel like it comes to an end when the paper is published and the study is over. The most exciting part of rheumatology research is watching our work create changes in the lives of our patients and resulting in real opportunities to improve patients' lives.



Outside of work Alyssa loves to dance – especially salsa

# EMEUNET: Bringing together the young EULAR community



Alessia (right) with Wendy Oldser from Young PARE

## Elena Nikiphorou, Alessia Alunno, and Sofia Ramiro, leaders of the Emerging EULAR Network, describe how the growing group supports young clinicians and researchers

With almost 2,000 members, the Emerging EULAR Network (EMEUNET) is, to date, the largest group of young clinicians and researchers in rheumatology. EMEUNET embraces all European countries and also welcomes members from outside Europe – with around one fifth of the members based in the United States, Egypt, Central and Southern America to cite a few.



Elena Nikiphorou

The main objectives of EMEUNET are to enhance the quality of education, to promote research by fostering collaborations and to facilitate the integration within EULAR of emerging rheumatologists and researchers in rheumatology. We strive to provide high quality educational and mentoring opportunities that are appealing to the wider European audience and beyond. We do this through several educational activities including peer-review training, podcasts and the Twitter journal club (in collaboration with the EULAR School of Rheumatology) and the EULAR journals (*Annals of the Rheumatic Diseases* and *RMD Open*).

*“EMEUNET members are integrated in EULAR Task Forces”*

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.



Alessia Alunno

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.

EMEUNET also has Ambassadors in 46 countries. They are the country liaisons who actively promote EMEUNET at a national level



Sofia Ramiro

and distribute EMEUNET/EULAR information, working in close contact with national rheumatology societies.

EMEUNET has also established a network with other young specialists' organisations in Europe, such as nephrology, paediatric rheumatology and immunology/allergy, to promote the development of a European-wide network of young clinicians from various fields and specialties taking care of people with RMDs.

With all these initiatives and activities, we are confident that EMEUNET will continue to be embraced by the young clinical and academic rheumatology community. This will make EMEUNET a successful and influential resource that fosters new and long-term collaborative endeavours and ensures that excellence in European rheumatology and EULAR is maintained.

*“EMEUNET will continue to be embraced by the young rheumatology community”*

## Paul Studenic and Alessia Alunno from EMEUNET showcase the collaborative approach of the Patient Reported Outcomes Task Force

The EULAR Task Force formed to develop points to consider/recommendations for including the perspective of young patients with inflammatory arthritis into patient-reported outcomes (PROs) is a major achievement of the fruitful collaboration



between European young rheumatologists and young patients. The idea was initially discussed back in 2016, during the first EULAR Young PARE meeting in Retie, Belgium that we attended as EMEUNET representatives.

The importance of identifying the unmet needs, priorities and expectations of young people with RMDs was a main theme of the meeting, and we all acknowledged that currently-existing PROs may not capture all relevant aspects of everyday life impacted by RMDs in young people.

*"It underscores the importance of close collaboration"*

The first phase of the project is currently ongoing and consists of qualitative analysis of data, gathered through focus groups carried out in five countries – Austria, Italy, Croatia, the Netherlands and the United Kingdom. This analysis represents the basis on which to build a European-wide survey to be distributed through PARE. The combined results will inform the Task Force members when developing



Paul Studenic

points to consider for including the perspective of young patients into the clinical assessment of young people with inflammatory arthritis.

We are confident

that the outcome of this Task Force will represent an important step forward in making the different needs of young people with RMDs heard and it underscores the importance of a close collaboration between young rheumatologists and young patients to successfully produce clinically applicable research outputs.

### **Ricardo Fereirra, nurse researcher from Portugal, provides the health professional perspective on the benefits of collaborating with EMEUNET**

Since its early beginnings, EMEUNET has welcomed young researchers from different backgrounds, not only rheumatologists. As a member since 2012, my experience has continued to get better and better. EMEUNET has presented me with multiple learning and networking activities. The epidemiology course, held annually in Berlin, was one of my first experiences – and one of the best. I repeated it twice (different topics) because, on top of having access to



The HPR's Ricardo Fereirra

a brilliant faculty, it was a great opportunity to meet people with the same interests. I've been linked to other alumni since then.

Although it is not mandatory to be a member of EMEUNET to participate in this course, members do have "privileged" access to information. Another advantage of membership is the improved experience of the EULAR and ACR Congresses for different reasons – we receive the Do not miss and the Highlights newsletters, we can participate in informal mentoring opportunities with top opinion makers and we participate in social events with peers.

Some of these experiences are similarly promoted by the EULAR Standing Committee of Health Professionals in Rheumatology (HPR) – for example, the mentoring programme. But, as HPRs, why not benefit from both?

*"Why not benefit from both experiences?"*

More recently, two of the most exciting opportunities offered by EMEUNET are the training programme to become a better reviewer through the collaboration of the *Annals of the Rheumatic Diseases* (ARD) and *RMD Open*, and the mandatory participation of two EMEUNET members

in all recommendations developed by EULAR. These are great examples of experiences that lead to better interdisciplinary collaboration between professionals in rheumatology. These, too, are only accessible for EMEUNET members.

*"HPRs have different and specific skills and perspectives"*

EMEUNET is a well-established community, with significant power to influence the development of educational and scientific opportunities for all young professionals in rheumatology. This would lead to better care conditions for patients. Thus, as well as patients benefiting in practice from multiple views, this network community also benefits from the same co-operation. Nurses, physio and occupational therapists, psychologists and other HPRs have different and specific skills and perspectives which, when combined, are more than the sum of their parts.

*"This combination of knowledge is important"*

Regarding research collaborations, a greater involvement of HPRs in EMEUNET can add value – for instance, qualitative research methods, interventions involving patient education, self-care management or psychological interventions to name only few examples. Combining different models of thinking, the health-disease process (biomedical, psycho-social, humanistic etc) is undoubtedly the way to go for better development. This combination of knowledge is important in every step of turning research – planning, implementation, interpretation and dissemination – into better practice, which is our ultimate aim.

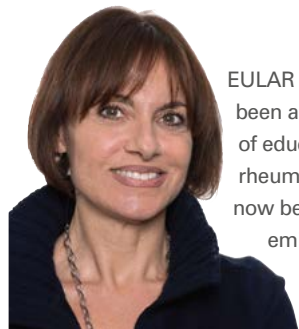
I strongly believe that both EMEUNET and the health professionals in rheumatology can benefit from tighter collaboration.



Elena from EMEUNET (2nd from right) participating in this year's EULAR Annual Conference of PARE

# EULAR School of Rheumatology gets underway

As the EULAR School of Rheumatology establishes itself, Annamaria Iagnocco, EULAR Treasurer and Past-chair of the EULAR Standing Committee on Education and Training, explains the benefits the school will bring



EULAR has traditionally been a strong supplier of education in rheumatology and has now become the pre-eminent provider and facilitator of high-quality educational

offerings for physicians, health professionals in rheumatology (HPRs) and people with rheumatic and musculoskeletal diseases (RMDs) worldwide. The benefits to the international rheumatology community of high levels of education in the field result in an increased knowledge of RMDs as well as the optimisation of their management. This leads to significant relief to the lives of people with RMDs.

With the objectives of providing high quality education supported by tailored learning materials and improving access to quality education in the field of RMDs, in June 2017 the EULAR School of Rheumatology (ESOR) was launched. This project is also aimed at

developing innovative learning methods and recognised EULAR certifications to evaluate and document acquisition of relevant knowledge.

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*“ESOR combines all educational offers under one roof”*

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ESOR is a fully integrated operational entity contained within EULAR, which combines all educational offers under one roof – whether they are live courses, online courses, books, webinars or any other material. By using this new system, members of the School will have facilitated access to all products with a personalised overview of the offerings and with the option to use the various incentives and special offers. Within their personal profile, members will also have a secure means of storing their gained certifications and other personal information.

Over the last two years, a team of experts has actively worked to develop new material to be added to EULAR’s already rich educational offer. These new products are addressed at different

target populations within the whole rheumatology community, and are tailored to their interests and field of activities. Many different projects are currently being developed by these “Classrooms” and are addressed to rheumatologists, undergraduates, trainees, teachers, researchers, HPRs and people with RMDs.

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*“Education opportunities are undergoing constant changes”*

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In today’s digital era, education opportunities are undergoing constant changes, with new approaches, products and technologies. Thus, the EULAR School of Rheumatology represents an innovative educational model and reflects the changing needs of learners through offering new materials as well as facilitating access to the highest quality of education in the field.

With the modern and rapid developments of the rheumatology discipline, ESOR is today taking its educational offerings, services and products to a global audience.

## Thea Vliet Vlieland, head of the HPR Classroom, provides the HPR perspective

The EULAR School of Rheumatology’s HPR Classroom currently has five members: Els van den Ende, Keegan Knittle, Eda Tonga, Sarah Ryan with myself as head. The members are supported by Annamaria Iagnocco, Catherine Haines and Dieter Wiek (PARE). In addition, Genevieve Schärer, EULAR’s Education Programme & Strategic Co-ordinator, plays an important role in facilitating the HPR Classroom members and their activities.

After the official launch of ESOR in 2017, the first meeting of the HPR Classroom was held 25-26 January 2018 in Amsterdam, the Netherlands. The aim was to develop a working plan for the HPR Classroom, based upon the educational strategies of EULAR and ESOR, the EULAR Standing Committee of HPRs and the preparatory work of the HPR Educational Sub-committee. A

second aim was to agree and develop concrete project proposals that had been prioritised by the Educational Sub-committee.

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*“We will strive to recruit additional members”*

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Regarding the working plan, the ESOR schedule will be followed – an annual meeting of Classroom members will take place each autumn and the development of project proposals must be submitted to the EULAR Executive Committee by an April deadline each year. Every Classroom can have a maximum of 10 members, so, with many projects ahead, we will strive to recruit additional HPR Classroom members to complement the current five.



Four potential project proposals were defined at our January meeting: a “renewed” version of the EULAR HPR Online Course, an HPR pocket primer to be included in the EULAR app, the HPR Mentoring Programme to be brought into the HPR Classroom, and a live Postgraduate course for HPRs to be organised in Spain. Decisions on these proposals are expected by September 2018.



# EULAR Public Affairs: Past, present and future

**Neil Betteridge, Liaison Officer, EULAR Public Affairs, highlights progress made in raising the profile of EULAR in the policy field**

With EULAR's current strategic plan coming to the end of its 5-year period, it is a good time to reflect on what has been achieved before we plan our next strategic goals. In public affairs terms, we have had a number of successes – some partial and some total – as well as one or two more ambitious goals which require further work!

Amongst the successes, I would include the following:

- rheumatic and musculoskeletal diseases (RMDs) are now recognised by EU institutions as one of the major chronic conditions, the evidence for this being their explicit mention in policy texts such as the Horizon 2020 Research Framework Programme
- WHO has also recognised RMDs for the first time in its new 5-year plan for Non-communicable Diseases
- every year, EULAR has organised a policy conference around World Arthritis Day, gathering together EU and national policy makers as well as the RMD community
- positions developed from these conferences mean that we have contributed to the development of EU policies in key policy areas (public health; research and innovation; and employment and social affairs), in part also because we have sustained the European Parliament Interest Group on RMDs
- EULAR delegations were received by key policy makers, for instance Dr. Vytenis Andriukaitis (EU Commissioner for Health and Food Safety)
- the RMD community is now represented in the main advisory board on EU health research
- under the leadership of Prof. Iain McInnes, EULAR has developed RheumaMap, the roadmap for research in RMDs (see below).

So, some real progress in raising the profile of EULAR and, most importantly, RMDs. But challenges remain and others will arise. New approaches will be needed in the next Public Affairs strategy – and the voice of health professionals in rheumatology (HPRs) will be vital in this.



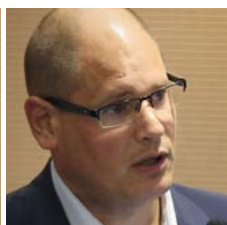
Brussels Conference: EULAR's Prof. Bijsma and Neil Betteridge with MEP Merja Kyllönen and Prof. Colm O'Morain, Alliance for BioMedical Research in Europe President

## World Arthritis Day Conference 2017

As part of EULAR's 2017 World Arthritis Day activities, EULAR organised the Conference "The future of health research and innovation after Horizon 2020. Do we need a novel approach?". The purpose was to contribute to the debates on the future of EU research, especially the next Research Framework Programme (2021-2027).



Takis Hadjigeorgiou



Timothy R.D.J. Radstake

The conference aimed to identify challenges in research and innovation in RMDs and other conditions, so as to develop policy recommendations. Two keynote speakers, Prof. A. Radstake (Utrecht University) and Prof. T. Radbruch (German Rheumatism Research Centre), identified key challenges in medical science and suggested how priorities in support of medical research should be defined.

In turn, EULAR President Prof. Johannes Bijsma presented RheumaMap. Developed by a group of EULAR clinicians, HPRs and people with RMDs, RheumaMap describes the state of play of RMD research, identifies key challenges ahead, and proposes recommendations to policymakers and funding institutions.

One of the conference workshops ("Challenges in transferring research findings and innovations into clinical practice") was led by EULAR's HPRs, in collaboration with the European Specialist Nurses Organisations (ESNO). Participants identified the main barriers to the implementation of research findings and made recommendations for overcoming these.

## A look ahead – EULAR Public Affairs activity in 2018

Research and innovation, access to healthcare, and health and safety at work are among the topics EULAR will keep working on in 2018.

The World Arthritis Day Conference will again be a major event. Entitled "Bringing chronic diseases to the forefront of health innovation: from the lab to health care" (working title) it will take place in Brussels on 9 October 2018. The aim is to develop recommendations on the development of the next EU Research Framework Programme (FP9); and innovative approaches in healthcare – for example the implementation of eHealth solutions for the diagnosis, prevention and management of chronic diseases.

It is really important that HPRs continue to be involved in all of these issues. Thank you so much for all your input to date.

Please contact [brussels@eular.eu](mailto:brussels@eular.eu) for more information on EULAR Public Affairs activities.

# Introducing Young PARE

**Young PARE's mission is to empower young people with rheumatic and musculoskeletal diseases across Europe, and to educate and inspire the youth of today to be leaders of tomorrow. Young PARE's Simon Stones highlights some of its exciting work**



Simon Stones is a member of the Young PARE Working Group

Young PARE exists to improve the quality of life of young people with rheumatic and musculoskeletal diseases (RMDs). It achieves this by raising the profile of these conditions and by creating a network of individuals who work in European countries on behalf of young people with RMDs. Young PARE is a Working Group of the Standing Committee of PARE. Chaired by Petra Balazova, our group consists of eight representatives from across Europe, all of whom have an RMD.

Our day-to-day activities are now fulfilled by five committees. These include: Country Liaisons; Digital Communication; Education; Newsletter; and Visibility and Global Affairs. Young PARE is in a strong position to engage in a wide number of activities, all while equipping an increasing number of youth advocates across Europe with the skills and confidence to become future leaders.

## Contributions to research

Young PARE is a proactive and dynamic group of individuals with links to many young people and organisations around the world. Research forms an important focus. Prior to the formation of Young PARE, our members were involved in conducting the PARE youth research project, a multi-method study which explored the needs and preferences of young people with RMDs aged between 18 and 35. The results of this research informed Young PARE's 2020 strategy, demonstrating the capacity of young people as competent researchers, when guided and supported by other professionals. Young PARE also reports on activities, including

presenting our work at the Annual European Congress of Rheumatology and the Annual European Conference of PARE.

More recently, Young PARE has been working in close collaboration with EMEUNET to identify and develop new research areas. One recent successful collaboration includes the EULAR Task Force to develop points to consider/recommendations for including the perspective of young patients with inflammatory arthritis into patient-reported outcomes. (See page 8-9 for more details.)

We have also been involved in a variety of different research initiatives, including: (i) standards and recommendations for the transitional care of young people with RMDs; (ii) points to consider for developing mobile health apps for patients with RMDs; and (iii) points to consider on assessment of competencies in rheumatology across Europe.

## Collaboration with HPRs

We are at a very exciting point in rheumatology, whereby patients and professionals are recognised as equal contributors in the development of robust and meaningful research. Health professionals in rheumatology (HPRs) bring their unique professional perspective and skill set, while patients bring their invaluable perspective of living with an RMD.

When the skills, insights and energy of patients, HPRs, rheumatologists and other researchers are integrated, the outcomes really are infinite! Involving patients in research is a requirement for EULAR Task Forces and for many funders. There should be "nothing about us, without us!"

## Top tips for including young people with RMDs

My first piece of advice is to be brave. It can often feel daunting when you want to involve young people with RMDs. HPRs are sometimes unsure where to find young people. Partnering with existing groups, like Young PARE, is a good first step since we are in contact with many young people with RMDs across Europe.

Secondly, you should embrace social media – it is a valuable tool in helping you to share your work with young people and could result in new partnerships. Ensure that your work is accessible to young people with RMDs. Enter into discussions with young people at the earliest opportunity so that you can collaboratively work out how best to involve them. Honest and coherent communication from the outset is fundamental to achieving the best outcomes.

Finally, make a commitment that you will involve young people in all aspects of your work – whether that be clinical practice, teaching or research. Young people need to be involved in teaching the next generation of HPRs, as well as shaping future research and clinical practice to enhance the quality of life of young people living with RMDs.

We look forward to strengthening our collaborative work with HPRs as we work together to transform the lives of young people with RMDs.

Visit [www.youngpare.org](http://www.youngpare.org) for more information.



Young PARE meetings involve much discussion and interactive working... and some fun!





# EULAR HPR winter meeting 2017



The city of Vienna welcomed the 2017 HPR winter meeting

The winter meeting of the Scientific and Educational Sub-committees of EULAR's Health Professionals in Rheumatology (HPR) took place in Vienna, Austria in November 2017. Members met together to discuss important topics relevant for HPRs all over Europe. After a comprehensive update in the plenary about ongoing projects, new national HPR member societies, the status of the EULAR RheumaMap, the PARE Conference, the awareness campaign Don't Delay, Connect Today, World Arthritis Day and different HPR activities in Brussels, work continued in two separate breakout sessions: one focused on science and the second on education.

## Scientific Sub-committee

By Erika Mosor

The Scientific Sub-committee mainly concentrated on a **EULAR HPR long-term research strategy for 2018-23**. Our strategy aims at improving and sustaining quality of life for people with rheumatic and musculoskeletal diseases (RMDs). With our new research strategy, we want to emphasise the importance of early prevention, optimised evidence-based care, innovation and necessary collaboration between patients,



health professionals, rheumatologist/physicians, scientists and other important stakeholders on the national and European level.

You can read more about the issues which are addressed in the final version of the research strategy on page 3 of this newsletter.

Our research strategy relates to the EULAR *RheumaMap* – a so-called roadmap for research in RMDs. It was developed by Prof. Iain McInnes and EULAR, drawing on the expertise of the European RMD community – from scientific societies to health professional and patient organisations. The EULAR *RheumaMap* identifies a number of unmet needs and main challenges in research and innovation in RMDs. It proposes key areas where long-term strategic efforts can help to reduce the enormous burden of these conditions in Europe.

We are aware that, in order to implement the EULAR HPR research strategy 2018-23 throughout the varying groups of HPRs and across disciplines, we need to receive more funding resources for HPRs' research. For example, at the EU level in close co-operation between different professions, centres and countries within Europe.



## Educational Sub-committee

By Thea Vliet Vlieland

At the HPR winter meeting in Vienna, the Educational Sub-committee of the EULAR Standing Committee of HPR had fruitful meetings which addressed a number of issues that are important for HPRs.

First, Annamaria Iagnocco gave a presentation about the remit and structure of the EULAR School of Rheumatology. In addition, Els van den Ende, convenor of the HPR Online Course, presented an update on the uptake and appreciation of the course. Finally, new areas for the further development of educational activities were discussed. In the future, these activities will be executed in the context of the EULAR School of Rheumatology and suggestions made have been passed on to the HPR Classroom members (see the article on the HPR Classroom on page 10).

Regarding the latter, the importance of executing sufficient evaluation of HPR educational activities was highlighted, so that HPRs can make suggestions for improvements or for the development of new educational activities. Moreover, some potential areas where HPRs and PARE could work jointly with respect to education were identified, such as the provision of information on HPRs' roles in the management of people with RMDs.

During the course of 2018, the terms of office of some Educational Sub-committee members will come to an end and new members will be actively recruited.

Overall, we had a very successful winter meeting with intense and lively discussions, critical questions and important input from all members. We have already discussed the important topics with the EULAR Executive Committee and will continue working on them at our next HPR Scientific Sub-committee meeting in Amsterdam.

# Learning from each other

**Dr. Kirsten Hoeper, Rheumatology Centre Managing Director from the Department of Immunology and Rheumatology at the Hannover Medical School, Germany reports on her educational visit to the Academic Rheumatology Unit and Rheumatology Department, Bristol Royal Infirmary, University West of England, Bristol, UK in early 2018**

Nurse-led care is still in an early phase of its development in Germany. However, the role of nurses has become more and more important due to new regimens for the treatment of patients with inflammatory rheumatic diseases and a decreasing number of outpatient clinics in Germany. Currently, the backlog for patients with inflammatory rheumatic diseases for an appointment with a rheumatologist is nine months or more. Consequently, new processes are needed to improve the treatment situation in Germany.

In January 2018, I had the exciting opportunity to make an educational visit to the Academic Rheumatology Unit, Bristol Royal Infirmary, University West of England, Bristol, UK. The visit was supported by an educational grant from the EULAR Health Professionals in Rheumatology (HPR).

The aim of my visit was to learn about managing nurse-led care in an outpatient clinic and to gain some in-depth insight on how to implement nurse-led care in Germany. In addition, I wanted to learn about the education nurses need to be able to work in nurse-led care, and what qualifications and requirements they need in daily routine. The second aim was to discuss research in nurse-led care with my focus being on research designs and outcome measurements.

The visit was organised with Dr. Mwidimi Ndosi, a Senior Lecturer in Rheumatology Nursing at the University of the West of



The team of nurses from Bristol Royal Infirmary, Rheumatology Department, shared their knowledge with Dr. Kirsten Hoeper

England and Honorary Researcher at University Hospitals Bristol. The visit included observing different nurse-led clinics and sharing research experiences with fellow HPR researchers at the unit.

## Objective 1: Education

My first objective was to gain more understanding on the type and level of education that nurses need to be able to provide nurse-led-care, and qualification and competence requirements needed for the nurses in daily routine. I learned that students gain an undergraduate degree in nursing. Upon finishing the degree, nurses will gain their professional registration with the Nursing and Midwifery Council (NMC), which is the body that regulates the UK nursing profession. To earn a Postgraduate degree, Nursing MSc courses are offered to qualified nurses wishing to obtain a Master's award. Keele University offers a Masters programme in Rheumatology and this is available to nurses specialising in rheumatology.

To further educate the HPRs in Germany, since 2006 curricular training has been offered by the German Association of Health Professionals under the auspices of the Educational Academy in Rheumatology. However, nurse-led care brings the tasks of the HPRs to a whole new level. Consequently, the curriculum needs to be adapted. Getting insight into different educational systems is of valuable help.

## Objective 2: Managing a nurse-led-clinic

My second objective was to gain more understanding of processes and managing nurse-led-care in outpatient clinics.

The first clinic I observed was the biologic-clinic which was headed by Tracy French, MSc, RN, leader of the nurse specialist team. It was planned that five patients would have an appointment that afternoon, each with a 40-minute time slot. I was introduced to two different patient pathways: the Rheumatoid Arthritis Pathway and Direct Access.



The pathway for new patients was especially of great help to me. To help nurses in Germany gain confidence in nurse-led clinics, a standardised described pathway with a focus on nursing for newly diagnosed patients with inflammatory arthritis will be of great value.

Equally helpful were the screening assessment sheets for patients with rheumatological conditions requiring biologic therapies. I greatly appreciate that Tracy provided me with all forms and sheets she has developed for documenting patient care so that I could have something to look at once I was back in Germany.

The next clinics I observed were medication support clinics run on two different days by Claire Rowsell, BSc (Hons), RN, and Helen Varley, BSc (Hons), RN. Here the focus was on either newly diagnosed patients at the start of therapy or patient follow-ups according to the pathway. The time slot was one hour for new patients and 30 minutes for returning patients. The first visit after diagnosis but before starting medical treatment highlighted the importance of putting the individual patient into focus and how nurses contribute to supporting and empowering the patient. The diagnosis was reviewed with the patient and the new therapy explained in detail.



Dr. Kirsten Hoepfer and Dr. Mwidimi Ndosi

The third clinic observed was the osteoporosis clinic run by Terrie Stocker, BSc (Hons), RN. This clinic assessed patients with primary and secondary osteoporosis prior to the next planned injection of the prescribed medication. Depending on the blood values, checked by the nurse, an appointment for the drug administration was provided. Advice was given regarding nutrition and training. Additionally, I was allowed to attend a DEXA scan.

I had valuable discussions with all nurses about how to introduce nurse-led care in Germany and the skills required. I learned a lot about the educational system for nurses in the UK.

### Objective 3: Research in nursing

My third objective was to gain more understanding of research designs, research in nurse-led care and outcome measurements in nurse-led care.

I had the privilege of being introduced to several different projects currently running at the Academic Rheumatology Unit at Bristol Royal Infirmary. It was great to meet a research group with such valuable expertise within different disciplines. During my visit, I had several discussions with Dr. Mwidimi Ndosi about how to implement research results into clinical practice. He emphasised that gaining evidence for a new approach in the care of patients is only the first step. In order to successfully get research evidence implemented in practice, an implementation study is required. Since I have no experience in implementation research, he provided valuable information and literature on this topic.

### Implementation in Germany

Nurse-led care has not officially been implemented in Germany so far. However, more and more outpatient clinics start processes by themselves. So far, no standardisation, handbooks or any other relevant tools have been established.

I started a randomised, multicentre trial on the effectiveness of nurse-led care in January 2018. Together with the participating nurses, it is planned to develop important evidence and tools to support nurses who want to pioneer innovative nurse-led care. With my valuable insight into how an established nurse-led clinic works, I have a better understanding of what is needed. My new knowledge

will be of great benefit to the planning and implementation of this model of care in Germany.

I have already shared and discussed new ways to introduce nurse-led care in our outpatient department at the Hannover Medical School. The clinical nurses at our hospital have a great interest in extending their role in daily practice. My research assistant started to translate the documents I received during my visit. This will help us to develop a handbook and training sheets for the nurses.

Another step will be to recruit more outpatient clinics interested in nurse-led care. The outpatient clinic "Rheumapraxis an der Hase" in Osnabrück already has experience with nurse-led care. The Clinical Nurse Specialist running the clinic, Patricia Steffens-Korbanka (also the vice-president of the HPRs in Germany), has agreed to have nurses from other clinics sit in with her during patient visits.

Together with the nurses at the centres participating in my study, I will develop an implementation study to follow on from the currently-running trial. This will help to ensure smooth implementation of research into clinical practice and the development of early centres of excellence in rheumatology nursing in Germany.

Lastly, I plan to share my experience of this educational visit during training courses for nurses and with other nurses within the EULAR Nurses Study Groups.

I have gained a profound insight regarding nurse-led-care and research in nursing in Bristol and have fulfilled all the learning objectives for the visit. I look forward to further collaboration with Mwidimi Ndosi and his group on future projects. I thank EULAR for the financial support and, therefore, contributing to this important and exciting experience.



# Reaching out

**EULAR continues to work towards growing its health professional network membership. We hear from two members about the work of their associations.**

## National HP member organisations of EULAR:

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

## From June:

Slovenia

● Visit the EULAR Health Professional website to find out how your country could apply for membership.

## Irish Rheumatology Health Professionals Society

**By Rhona Galway, Past Chair, on behalf of the Chair and Committee of the IRHPS**

The Irish Rheumatology Health Professionals Association (IRHPS) was founded in 1996 and became a member of EULAR in 2013. Through multidisciplinary and multi-centre representation, the IRHPS aims to promote the optimal care of patients with rheumatic and musculoskeletal diseases (RMDs) throughout Ireland.

### Working in two nations

Within EULAR we are in the unique position that our members live and work in two nations – in the Republic of Ireland, and in Northern Ireland as part of the United Kingdom. This provides a valuable opportunity for our members to share experiences of quality service provision across two healthcare systems and to form valuable educational links.



Members of IRHPS Committee 2017

The association has annual assembly meetings, scientific meetings and attends EULAR congresses. We also take part in the celebration



Presenters at IRHPS 2017

of World Arthritis Day with local patient organisations. The autumn scientific meeting provides an excellent learning opportunity for members through the provision of lectures by world class speakers including international and local health professionals. With the support of pharmaceutical companies, the IRHPS also offers a variety of educational opportunities and bursaries to our members.

### There for our members

The IRHPS provides an expert resource for all members, affording opportunities to network locally, nationally and internationally. As an association, we continuously strive to improve the quality and standards of multi-professional care to patients with RMDs. We also encourage and facilitate multi-professional education, and

the development and dissemination of multi-centred research.



Prize Winners 2017

The association facilitates educational meetings which provide opportunities for the professional exchange of expertise, knowledge and skills in order to enhance the varying professionals in their clinical practice.

Visit [www.irhps.ie](http://www.irhps.ie) for news and events.



# Österreichische Gesellschaft für rheumatologische Gesundheitsberufe

## By Simone Luschin, President of the Austrian Society of Health Professionals in Rheumatology

The Austrian Society of Health Professionals in Rheumatology (ÖGRG) was founded by Univ. Prof. Dr. Tanja Stamm, PhD and Michaela Stoffer-Marx, PhD MSc in March 2011 at the Medical University of Vienna.

During her first presidency, Michaela Stoffer-Marx achieved some of the most important achievements: the ÖGRG partnered up with the Austrian professional organisation of rheumatologists (the ÖGR – Österreichische Gesellschaft für Rheumatologie) and, in 2013, the ÖGRG also affiliated with EULAR. This was the first time that Austrian health professionals in rheumatology (HPRs) had become a member of an international organisation. Both achievements are significant because our association aims to foster close relations between all health professionals in rheumatology.

The ÖGRG's Executive Committee is elected by the General Assembly for a term of two years. It consists of a President, Past-President, President-Elect, General Secretary and a Treasurer.

The members of the managing board deal with administrative and financial matters, and are responsible for the educational and scientific content of the annual meeting. They also establish standards for the training of health professionals in the field of rheumatology. In addition, the ÖGRG offers a newsletter service informing members about current topics of rheumatology and event previews.



Simone Luschin

## Current projects

We would like to highlight two projects currently being run by our association:

1. rheumatological training for health professionals
2. an annual meeting for health professionals working in rheumatology.

Our organisation works with, co-operates and is supported by the professional organisation of rheumatologists (ÖGR). The rheumatologists' association and the health professionals' association had a shared aim of establishing training for health professionals in the field of rheumatology. This is now a reality – the course is open to all HPRs and is held every other year. It is organised in five modules and we are glad that a lot of the most experienced specialists in Austria support our initiative by teaching the latest from research and clinical experience.



ÖGRG's other Executive Committee members: Bettina Binder, Michael Zauner, Patrizia Frenz and Sylva Taxer

Since the outset, the ÖGRG has organised a two-day annual meeting for our members. The meeting is dedicated to a specific topic, focusing on the interests of health professionals. Different experts are invited to give talks and workshops according to the subject. The event is supported – but not influenced – by different companies. Therefore, attendance is free of charge for the delegates.

## Scientific Advisory Board

Recently, the ÖGRG established an HPR Scientific Advisory Board to support and advise the Executive Committee on scientific matters including the national congress programme, potential scientific projects and funding options. We include a variety of different health professionals (as well as rheumatologists and patients) with research experience and will meet twice a year. As a first task, the Scientific Advisory Board will develop a strategy for the successful transfer of knowledge from research to practice for Austrian HPRs. In addition, members of the Scientific Advisory Board will inform about scientific possibilities, such as educational visits for HPRs, give advice on abstract writing for congresses and support people to receive travel bursaries for attending the EULAR congress.

Visit [www.rheumatologie.at/gesundheitsberufe/](http://www.rheumatologie.at/gesundheitsberufe/) for more information.

## EULAR Health Professional Membership Directory

EULAR's *Directory of Health Professional Member Organisations* is available on the EULAR website. You can learn all about the country members including a breakdown of organisational member specialties and

details of societies' main activities.

One of EULAR's main priorities is to strengthen the health professional network. This directory is a tool to increase your

level of knowledge about each other. Becoming part of the HPR network offers a wealth of opportunities to national health professional associations and their members.

Visit [www.eular.org/health\\_professionals\\_member\\_orgs.cfm](http://www.eular.org/health_professionals_member_orgs.cfm) to view or download your copy of the directory.

# Health Professional Study Groups: The way forward



**By Dr. Yeliz Prior, co-opted member of the EULAR Scientific Committee and Study Groups Co-ordinator**

EULAR Study Groups (SGs) are established networks in their respective fields and play an active part in the research and treatment of rheumatic and musculoskeletal diseases (RMDs). In the previous issue of this newsletter, our EULAR Vice President representing Health Professionals in Rheumatology (HPRs), Prof. Tanja Stamm, emphasised the need of HPRs to focus on large European grants as well as on current big data initiatives to create better evidence for our interventions. So, how can the EULAR HPR SGs work towards this objective?

## Person-centred healthcare delivery

Due to inherent homogeneity amongst the HPRs' clinical role in people with RMDs, there is a propensity

towards conducting research to investigate discipline-specific interventions in rehabilitation of RMDs – for example, physiotherapy, occupational therapy, nursing. In contrast, HPRs deliver interventions as part of a multi-disciplinary team (MDT) in clinical practice, with an understanding that each profession contributes to a person-centred healthcare delivery. Each brings their own knowledge base, clinical skills and philosophy towards the treatment to enhance patients' journeys through the healthcare systems. This, in turn, reflects on the associated patient reported outcomes which are measured to ascertain the effectiveness and cost-effectiveness of such complex HPR interventions.

Henceforth, EULAR is encouraging new SG applications to base their

remit around research themes – for example, patient reported outcomes, self-management of RMDs. This will bring HPR MDTs together to use their collective expertise to investigate some of the established and emergent research questions, instead of discipline-specific SGs which could limit the sphere of research activity. As the Study Groups are endorsed on the basis of being multi-national (i.e. at least five different countries should be represented in each study group), this should also help tackle – to an extent – the variability amongst HPRs' knowledge and skill set across EULAR member states.

## Actively involve people with RMDs

Additionally, and most importantly, EULAR is encouraging SGs to include

Patient and Public Involvement and Engagement (PPIE) within the development of specific research questions and their application to research grants. This will ensure that people with RMDs are actively involved in the research process itself rather than just being the participants of the research. This is of paramount importance in delivering relevant and good quality research outcomes – the main objective behind large European grants and big data initiatives.



Dr. Yeliz Prior

Further information about the activities of the EULAR SGs, how to join them and how to apply for a new Study Group is available online at [www.eular.org/health\\_professionals\\_study\\_groups.cfm](http://www.eular.org/health_professionals_study_groups.cfm). Please remember that **SGs are open to anyone who wishes to join them**. Please feel free to contact me at [y.prior@salford.ac.uk](mailto:y.prior@salford.ac.uk) to discuss any ideas or queries you may have. I will be more than happy to help and, if necessary, steer you in the right direction.

## EULAR Congress 2018: Study Group meeting schedule

Study Group	Date	Time	Room	Study Group Leader	Email
Nurse Research & Strategy Group (REST)	14.06.2018	17:00–18:00	D404	Yvonne Eijk Hustings	<a href="mailto:yvonne.eijk.hustings@mumc.nl">yvonne.eijk.hustings@mumc.nl</a>
Clinical Nurse Study Group	14.06.2018	17:00–18:00	D304	Jenny de la Torre	<a href="mailto:delatorre_jen@gva.es">delatorre_jen@gva.es</a>
Physical Activity & Exercise Group	14.06.2018	18:00–19:00	D304	Rikke Moe	<a href="mailto:rikmoee@gmail.com">rikmoee@gmail.com</a>
Foot & Ankle Study Group	14.06.2018	17:00–18:00	D408	Gabriel Gijon Robert Field	<a href="mailto:gagijon8@gmail.com">gagijon8@gmail.com</a> <a href="mailto:rfield@nhs.net">rfield@nhs.net</a>
Study Group on Patient Education (STOPE)	14.06.2018	17:00–18:00	D402	Mwidimi Ndosi	<a href="mailto:mwidimi.ndosi@uwe.ac.uk">mwidimi.ndosi@uwe.ac.uk</a>



# Amsterdam

## 13–16 June 2018

The EULAR Annual Congress of Rheumatology in Amsterdam 2018 will see high quality scientific sessions for health professionals in rheumatology (HPRs) which introduce research and issues of interest in HPR practice. You will have the opportunity to attend 14 HPR sessions, including two abstract sessions and two joint sessions which have been organised with rheumatologists and PARE. Additionally, HPs can take part in two dedicated poster tours.

The HPR booth will be located with the other EULAR pillars in the EULAR Village. Come and visit us: it is an ideal opportunity to visit the Health Professional Standing Committee and network with colleagues.

Visit the official website at [www.congress.eular.org/](http://www.congress.eular.org/) or download the Congress app to your smartphone to access the full congress programme.

## EULAR Congress 2019

12–15 2019

Madrid, Spain

Visit the Congress website from summer 2018 to access information about abstract submissions for the 2019 Congress

[www.congress.eular.org](http://www.congress.eular.org)



### The Health Professional Programme 2018

Date	Session title	Session type	Room
13 June 14.15 – 15.45	HPR Welcome Session	HPR session	Amtrium
13 June 16.15 – 17.45	New drugs – new perspectives: clinical and regulatory issues concerning biosimilars	HPR / PARE session	Amtrium
13 June 18.15 – 19.45	Delay in treatment and the role of health professionals	HPR session	Amtrium
14 June 10.15 – 11.45	HPR Abstract Session: Singing power to the people	HPR abstract session	Amtrium
14 June 11.45 – 13.30	Poster tour T14: Winds of change	Poster tour	Poster area
14 June 13.30 – 15.00	Sustainable Healthcare in Rheumatology and the Role of Health Professionals	HPR session	Amtrium
14 June 15.30 – 17.00	It's your move: Promoting Physical Activity in people with RMDs	HPR session	Amtrium
14 June 15.30 – 17.00	The EULAR exercise recommendations for physical activity in people with inflammatory arthritis and osteoarthritis	EULAR Projects in HPR	E106 / E107
15 June 10.15 – 11.45	HPR Abstract Session: Supporting self-management	HPR abstract session	Amtrium
15 June 11.45 – 13.30	Poster tour F15: Bread and butter for clinicians	Poster tour	Poster area
15 June 13.30 – 15.00	New approaches in measuring what matters to patients	HPR session	Amtrium
15 June 15.30 – 17.00	Navigating the world of digital health	HPR session	Amtrium
16 June 09.00 – 10.30	Multi-disciplinary management of complex persistent pain	HPR session	Amtrium
16 June 12.00 – 13.30	How do you sleep?	HPR session	Amtrium
16 June 12.00 – 13.30	Work and rehabilitation – key priorities for people with RMDs	PARE / HPR session	PARE room
16 June 13.45 – 14.45	HPR Highlight Session	Highlight session	Amtrium

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

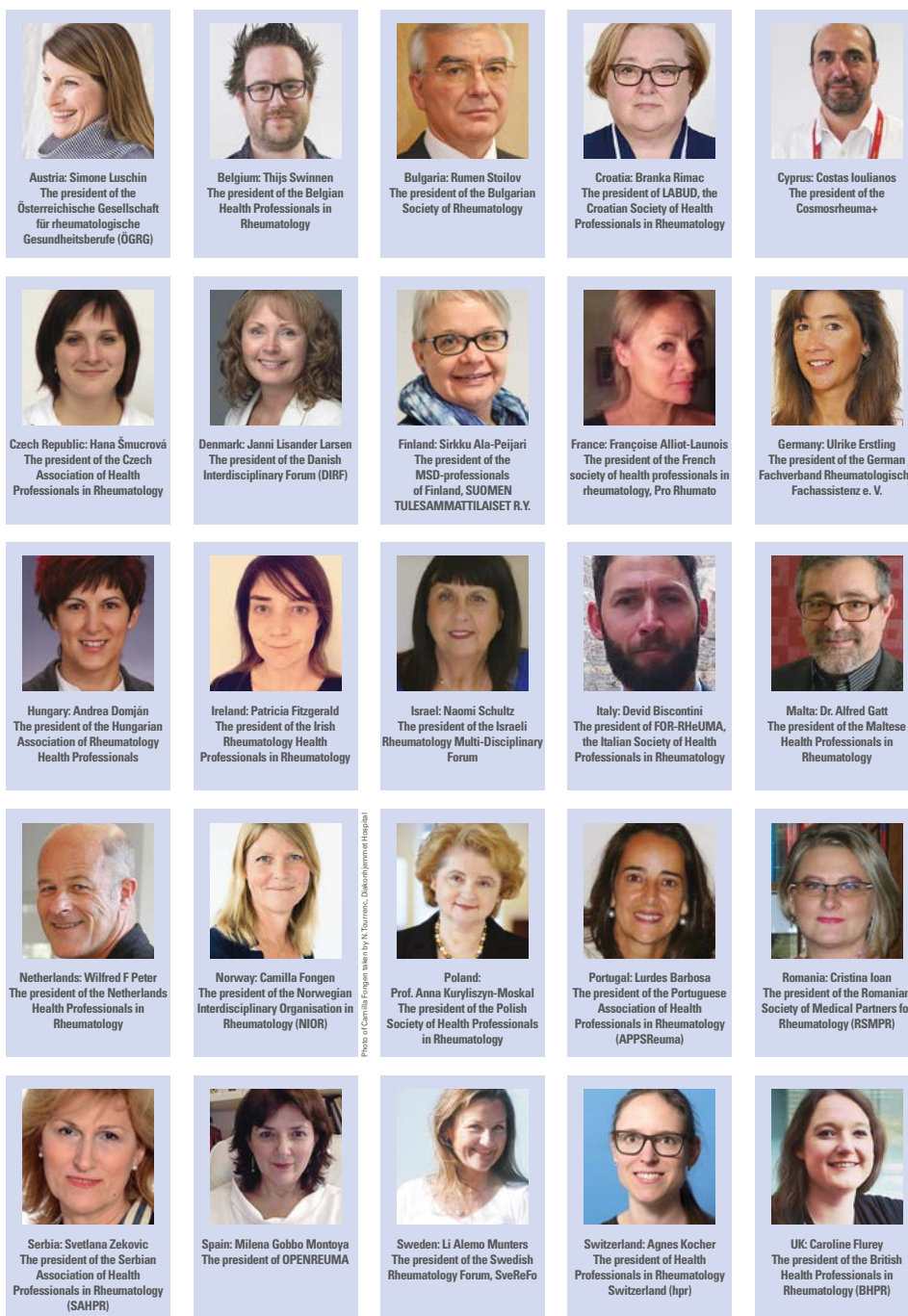
There are 25 formally ratified EULAR HPR organisations represented by their presidents or other nominated officials on the EULAR Standing Committee of Health Professionals in Rheumatology.

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

The Committee, headed by Chair Annette de Thurah, Chair-Elect Rikke Helen Moe 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.

Annette de Thurah: annethur@rm.dk  
Rikke Helen Moe: rikmoe@gmail.com  
Tanja Stamm: tanja.stamm@meduniwien.ac.at



**From June: Slovenia**

**For contact details, please visit**

**[www.eular.org/health\\_professionals\\_member\\_orgs.cfm](http://www.eular.org/health_professionals_member_orgs.cfm)**

## Editorial office

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