12 October is a well-known and important day: World Arthritis Day is designed to create awareness around the existence and impact of rheumatic and musculoskeletal diseases (RMDs) on people everywhere. In 2017, World Arthritis Day was celebrated with the EULAR campaign, Don’t Delay, Connect Today, which was launched in June this year at the EULAR Annual Congress of Rheumatology in Madrid, Spain.

EULAR has developed a dedicated video around this campaign which was launched on World Arthritis Day: Three people, each living with a different RMD, share their personal story. Emotive and personal, the stories are designed not only to educate the viewer, but also to inspire: For these three people, early diagnosis and access to excellent care has provided them with the chance to adapt and learn to manage their health needs, while living a fulfilling life.

The Don’t Delay, Connect Today campaign was developed by EULAR’s three membership pillars – patients with arthritis and rheumatism in Europe (PARE), health professionals in rheumatology (HPRs) and the scientific communities. Addressing society at large, the campaign has been designed to raise awareness and understanding of RMDs and to motivate people to recognise possible health warning signs that their bodies may be experiencing, and to act immediately by contacting their healthcare provider.

Early diagnosis is key to preventing further damage, but RMDs often receive delayed or no diagnosis. This is often due to a lack of awareness, thereby reducing quality of life, affecting physical ability and, ultimately, placing a devastating psychological burden on the individual – and on healthcare systems – which could otherwise be avoided.

HPRs are encouraged to get involved with the campaign. This could be through campaigning at the local or national level, collaborating with your national patient association or promoting the campaign video (which is being translated into different languages). EULAR has tried to make this easy for you by developing a toolkit especially for health professionals in rheumatology. You can read more about this from the HPR perspective on page 10 of this newsletter.

Will you #ConnectToday?

For more information, visit eular.org/what_we_do_dont_delay_connect_today.cfm and follow EULAR on Twitter, Facebook and LinkedIn.

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

Act quickly: the application deadline for the 2018 HPR Research Grant is 8 December 2017.
Welcome to the autumn EULAR HPR News. Since our last issue, many of you gathered in Madrid for the EULAR Annual European Congress of Rheumatology. If you were not able to be there, open this newsletter at page 8 to read the session highlights from two of your colleagues.

This issue highlights EULAR’s new campaign Don’t Delay, Connect Today which aims to raise awareness of early diagnosis and early treatment of rheumatic and musculoskeletal diseases. Many of the articles discuss how health professionals in rheumatology can get involved and campaign nationally.

Our Big Interview this issue is with President Elect, Prof. Iain McInnes, who shares his thoughts on future priorities. You can read all on page 6.

Enjoy your read.

If you have any ideas, don’t keep them to yourself. You can get in touch with me any time by emailing 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

Ever since 2000, the HPR Newsletter has provided the main information channel of health professionals in rheumatology (HPRs) and show what we are brilliant at! We want to become the greatest at getting the most out of each drop of health. Together with people with rheumatic and musculoskeletal diseases (RMDs) and rheumatologists, we are specialists in how to live healthily with RMDs – but also in promoting musculoskeletal health and preventing RMDs. This includes knowing our specific strengths when meeting challenges in complex areas like prevention, integrated care and rehabilitation.

I work as a physiotherapist and researcher at the National Advisory Unit on Rehabilitation in Rheumatology in Oslo, Norway. For about 20 years now, I have worked within the field of rheumatology as a clinician and a researcher. I am national president of the Norwegian rheumatology health professional organisation (NIOR) which is a member of the EULAR HPR network. I have been active in EULAR in various ways – as a member of the Scientific Sub-committee of health professionals and leader of the physiotherapy and physical activity Study Group. Now I am delighted to have been elected Chair Elect of the HPR Standing Committee.

Working together across borders is inspiring. I learned so much taking part in the EUMUSC.NET project, funded by the EU and EULAR, where I had the pleasure of working closely with researchers, clinicians and patients from several European countries over time. My major research interest is how to ease the burden of RMDs from a multidisciplinary view, especially regarding clinical and epidemiological aspects of functioning, disability and health.

The breadth of activity in EULAR is enormous. For the next couple of years, we, the EULAR HPRs, will continue our representation across all EULAR’s activities and keep on developing projects and strategies through our educational and scientific Sub-committees. We will use the possibilities that EULAR’s School of Rheumatology is opening up to us, keep up good session planning to achieve the best possible congress programmes, and support our national HPR member organisations as they continue to grow. We will follow up with abstract scoring, bursaries and prizes. Educational visits are one example of an activity which is more important than ever – with the increasing burden of RMDs in our society we continuously need to learn from each other and cooperate.

Working together with the EULAR Secretariat makes me humble – they work very hard to manage and support the activities of all three EULAR pillars to make everything happen.

The sparkles in my life are my sons and, in my spare time, I happily coach the local junior handball team. A couple of times a year I take the boys hiking, leaving the computer behind.

Dr. Rikke Helene Moe, Chair Elect of the EULAR Standing Committee of Health Professionals in Rheumatology, introduces herself and shares what inspires her

To me, it is important that we step up as health professionals in rheumatology (HPRs) and show what we are brilliant at! We want to become the greatest at getting the most out of each drop of health. Together with people with rheumatic and musculoskeletal diseases (RMDs) and rheumatologists, we are specialists in how to live healthily with RMDs – but also in promoting musculoskeletal health and preventing RMDs. This includes knowing our specific strengths when meeting challenges in complex areas like prevention, integrated care and rehabilitation.

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EULAR physical activity recommendations

By Prof. Karin Niedermann, PhD, PT, from Switzerland

EULAR-endorsed physical activity (PA) recommendations were developed for inflammatory arthritis (IA), including rheumatoid arthritis (RA) and spondyloarthritis (SpA), and osteoarthritis (OA) during 2017. PA broadly encompasses exercise, sports and physical activities done as part of daily living, occupation, leisure and active transportation. Exercise, as a subset of PA, is, however, planned, structured and repetitive activity to improve or maintain physical fitness. The recommendations constitute a bridge between arthritis-specific exercises and public health recommendations for PA.

In accordance with the EULAR Standard Operating Procedures (SOP, van der Heijde 2014), two task force meetings were held with international experts. The task force consisted of 22 experts from 15 European countries – six MDs, including three rheumatologists, a specialist in cardiovascular diseases, a GP and an orthopaedic surgeon; nine physiotherapists (PTs); a psychologist, an occupational therapist (OT); a nurse; a human movement scientist and three patient research partners.

The first task force meeting, held at the end of January 2017, formulated the research questions which would cover the areas of interest for recommendations and which would, subsequently, drive the literature review. Under the supervision of the methodologist Prof. Thea Vliet Vlieland (the Netherlands), the rheumatologist Prof. Jürgen Braun (Germany) and me as the convenor, the fellow, Anne-Kathrin Rausch, PT, reviewed the literature to answer the research questions for all three conditions from February to the end of September 2017. PA and exercise were always considered separately.

The evidence for the various questions was presented at the second task force meeting. Based on these results and the expert discussions, the recommendations for PA were developed. The discussion among the task force members, representing different professional and cultural backgrounds, lead to a broad consensus on the formulation of the recommendations. After the meeting, an individual and anonymous rating on the final recommendations among the task force members was performed, according to the EULAR SOPs.

The recommendations on PA for people with IA and OA are an important contribution, drawing attention to the crucial role of PA (promotion) in the care of people with these conditions, and better using its potential. The recommendations also meet one of EULAR’s strategic aims as they intend to support patients and all healthcare providers involved.

Act now for 2018

Registration for the EULAR Annual European Congress of Rheumatology 13-16 June 2018 in Amsterdam, Netherlands is now open. Register before 31 January 2018 to take advantage of the early registration fee.

Abstract submission is open until 23:59 CET 31 January 2018. 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/travelbursary_application_form.cfm when submitting your abstract.
Optimising non-physician care in osteoporosis

By Emalie Hurkmans, PhD, health consultant from Ecorys, Rotterdam, Netherlands and joint HPR lead of the EULAR task force on prevention and management of osteoporotic fractures

Osteoporosis is a progressive disease of the skeleton characterised by low bone mass and micro-architectural deterioration of bone tissue resulting in an increased risk of fragility fractures1. Frailty fractures require immediate acute fracture care and can lead to physical disability, pain, impaired quality of life, increased mortality and higher healthcare costs2-4. Among those who have already sustained a fracture, the risk of subsequent fractures is roughly doubled5, 6.

Multidisciplinary interventions delivered by non-physician health professionals, such as physiotherapists, occupational therapists and nurses, play an important role in effective support and management of patients with osteoporosis. Interventions include falls prevention, assistive devices, adaptation of environment, functional training, exercises, screening programme. Antiosteoporotic drug therapy is important, and the role for health professionals (HPs) in education and adherence to medication is also important. In some EULAR member countries, HPs can also prescribe antiosteoporotic drugs.

Currently, no international recommendations / points to consider on falls and fractures have been developed for this patient group. Our EULAR HP task force aims to establish collaborative EULAR points to consider / recommendations for the prevention and management of osteoporotic fractures through a collaborative defined process.

This collaborative process will:

1. establish an international expert panel/ task force to include patients and representatives from relevant HPs and multidisciplinary teams
2. identify specific clinical questions through Delphi consensus
3. conduct a systematic literature review (SLR) searching for evidence on these questions in order to formulate targeted points to consider/ recommendations
4. develop general consensus and agreement with our expert panel and then we will field test these recommendations.

The task force has been formed and, through a systematic process, we have identified 8 clinical questions on the diagnostic procedures, effectiveness of (multidisciplinary) interventions (primary and secondary prevention), education, implementation of recommendations, promotion of antiosteoporotic adherence and bone health review. Over the next months, the SLR will be conducted on these identified clinical questions, and the EULAR task force will meet in November 2017. The preliminary recommendations are expected by the end of January 2018.

This project will support the EULAR Standing Committee of Health Professionals in Rheumatology to optimise the non-physician care for the patient with osteoporosis and risk of a fragility fracture and/or (subsequent) falling.

Quality improvement

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

I will start my column with a little retrospect on our 30th Anniversary celebration in Madrid. For me, personally, it was a great experience and honour to meet three of our founders during the congress: Vicky Stephenson from the UK, Angelika Kruse-Jensen from Norway and Ulla Nordenskiöld from Sweden. Thank you to them for joining us in Madrid. Today, we build on all their hard work and owe them a depth of gratitude – they were the true pioneers.

Now we are looking forward and planning for the 2018 congress in Amsterdam is in full swing. Every March the HPR Chair puts out a call for session proposals. We receive many fine and relevant proposals that we can develop, and we are very grateful for that. However, I will take the opportunity to urge all of you to send in proposals. It need not be a description of a full session and you need not suggest speakers. You can also just suggest a subject or an idea for a session that we can work on. We want the HPR congress sessions to be up to date with what is new in our area, just as we strive to have sessions reflecting the needs of our members.

The 2017 congress was not only our celebration year, it was also the year where we set a record with respect to the total number of abstracts submitted to the HPR Chair. We received a total of 323 abstracts and approximately 15% of these were scored as “very good”. This is very promising and a sign that we have reached a milestone in one of the HPR strategic goals saying that: by 2017, EULAR will have increased the quantity and quality of HP-led research projects and strengthened patient participation. It makes me very proud and it is really a treat to be part of this process of development.

As I write these lines, the abstract system has just opened, and we are looking forward to receiving all your fine abstracts over the next months. Keep up the good work!
Don’t delay, change your future today

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

Will the EULAR campaign Don’t Delay, Connect Today change the future of health professionals in rheumatology (HPRs) in Europe? I am convinced that this campaign has the potential to change the roles of HPRs. New models of care, for example in primary care, will create excellent opportunities in many European countries for health professionals to work in new settings. HPRs will be key people in terms of early referral of people with rheumatic and musculoskeletal diseases (RMDs). They will refer patients to the right medical specialist(s) including rheumatologists. Don’t Delay, Connect Today is, therefore, the core topic of our newsletter.

“A further issue regarding early referral and timely treatment is the evidence-based treatment of patients with osteoarthritis (OA) that many health professionals, especially physiotherapists, nurses and occupational therapists, excellently deliver in various European countries. Without HPRs, patients with OA would have less quality of life and substantially decreased function in daily living activities. Pain in joints, loss of function, but also aesthetic changes related to hand OA can be important HPR intervention targets. Our interventions are individualised and personalised to the needs of each single patient, and these interventions need to be delivered as early as possible in the course of the disease. So again, early treatment is an important issue.

A third area that would need the more intensive focus of health professionals is prevention and health promotion at the workplace. We are specialists in physical activity, occupations, paid work, ergonomics, movement, and the planning and conducting of activities. Health promotion concerning (but not limited to) RMDs and (primary and secondary) prevention for people with RMDs in the workplace will make the lives of many people better. People commonly spend a considerable amount of their lifetime at the workplace. Furthermore, people also work at home, for example in home offices, when doing housework, taking care of children and/or grandchildren. Leisure activities also benefit from an ergonomic, physiological and health-promoting way of doing things.

References:

Health promotion and early prevention should start early in life: kindergartens and schools should be important targets for future activities in this area.

Taken together, early referral in primary care, evidence-based treatment in osteoarthritis, and health promotion and prevention in RMDs in the workplace will be important future areas for health professionals to be involved. HPRs can contribute substantial knowledge and clinical expertise for the benefit of the large number of people in Europe.
As Prof. Iain McInnes settles into his new role as EULAR President Elect, HPR News talks to him about his future priorities and the role he foresees for health professionals in rheumatology.

Could you tell us a little about what you do and what motivates you in your work?

I am a clinical rheumatologist working in the University of Glasgow. I have several formal titles, including Muirhead Professor of Medicine, Arthritis Research UK Professor of Rheumatology and I also have the privilege of serving as the Director of the Institute of Infection, Immunity & Inflammation. My clinical work is conducted in Glasgow Royal Infirmary in the Centre for Rheumatic Diseases which was founded over 50 years ago. Taken together, this is an exciting and diverse range of activities. My motivations are primarily driven by curiosity to understand the nature of inflammatory arthritis and to seek the very best treatments that might be possible for people so afflicted. Ultimately, it is the experience of my patients that drives the research and educational activities which are so important to me.

EULAR has been an important part of my rheumatological life for many years – and, on reflection, it has been a remarkable journey of learning and illumination for me. I had the privilege to serve as Abstract and Scientific Committee Chair for the Annual Congress, as Chair of the EULAR Standing Committee on Clinical Affairs, as Chair of the Combined Standing Committees and, thereafter, as the EULAR ACR Liaison Officer, working to bring together the visions and ideas of North American and European rheumatology. During this period, I am particularly proud of the increased interactions that have been enjoyed by health professionals in rheumatology (HPRs) in these two global regions, to mutual benefit.

Recently I served as EULAR Treasurer and was honoured and delighted to take the position of President Elect in June 2017. EULAR is an extraordinary organisation with tremendous and powerful possibilities to improve the lives of people with rheumatic musculoskeletal diseases (RMDs) across Europe and beyond. It is an enormous privilege to be able to contribute to this community.

You have led RheumaMap, EULAR’s research roadmap project. How will it support EULAR’s work and, especially, the work of HPRs in the coming years?

RheumaMap is an important document which lays out the key unmet needs of – and potential routes to progress for – people with RMDs. The taskforce that created it comprised all the constituencies contained in EULAR. Our HPR colleagues brought much-needed insight into the dynamic and progressive possibilities that can be focused to address these unmet needs on the part of the HPR community. RheumaMap does not define necessarily the “only” way in which unmet needs should be resolved, but serves rather as a blueprint. I would urge colleagues to read the RheumaMap and bring their own innovation, creativity and imagination to resolving the problems that face our patients.
What difference do you think **RheumaMap** can make to the lives of people living with RMDs?

*RheumaMap* has, at its core, a vision whereby we will reduce suffering currently imposed by RMDs, leading eventually to the achievement of remission in as many as possible and, ultimately, to the prevention of RMDs. The latter is a long-term vision but surely something to which we should aspire? And, if nothing else, *RheumaMap* should serve as the catalyst to achieving this ambition!

What is the key message you think policymakers need to take away and work to address?

RMDs matter! They impose enormous suffering upon the individual afflicted, upon their families, but also upon the communities within which RMDs cause substantial socio-economic burden. Policy makers should understand that, with appropriate early recognition of disease, “state-of-the-art” treatment delivered by multi-disciplinary teams of appropriately trained experts fully engaged in partnership with patients, we can substantially reduce the burden of RMDs to the benefit of all in society. It is critical that we offer policy makers key actions that will allow us to furnish this global vision. Practical achievable programmes of work will always offer the optimal possibility of progress. I am a great believer in presenting policy makers not only with the problem, but also with potential solutions. It seems to me that EULAR is ideally placed to deliver such solutions.

What can HPRs do to support the **RheumaMap** in their own nations?

It is vital, in the first instance, that health professionals support *RheumaMap* dissemination within their own national constituencies. Its ambitions and recommendations are applicable across Europe, but they will always travel better if given local context, flavour and application. Given their unique insights across the challenges faced by people with RMDs, HPRs can play a critical and pivotal role in making sure the messages reach other health professions, healthcare providers and policy makers. In the longer term, I hope that HPRs will shape the next iterations of *RheumaMap* at the global strategic level.

Don’t Delay, Connect Today is an important campaign for EULAR. How can EULAR ensure that early intervention in inflammatory arthritis doesn’t overshadow HPR work in other RMD areas?

Don't Delay, Connect Today is a very exciting effort to ensure that early recognition and intervention in arthritis can be offered to the majority of people developing RMDs across Europe. I recognise the concern that this focus on early disease, however admirable, may distract us from the other pivotal challenges that we face in the management of people who already have arthritis or, indeed, other established RMDs. EULAR is acutely aware of this risk and we see a number of initiatives emerging that will focus on the needs of those with already established disease. Many of our taskforces are concerned with the management of those who already have RMDs – EULAR will continue to work to update these and to ensure that they are rigorously and meticulously applied.

Can you foresee any changes in the way HPRs can be involved in research in the future? What difference do you see Brexit making to RMD research?

One of the great successes of EULAR has been the integration of health professionals, people with RMDs and rheumatologists working together to seek common solutions to common problems. As we seek to resolve the challenges of the future, it seems critical to me that HPRs continue to play a fundamental role in defining the unmet needs, in establishing projects that seek solutions and then ensuring that solutions, once established, are delivered on the ground. It will be essential that there is a strong training element delivering high quality research skills amongst HPRs. Capacity building and training will, therefore, be a very important element delivered through the EULAR School of Rheumatology. As the quality of research skills further extends within the HPR community, so too their capacity to deliver will increase. In this beguiling “molecular age”, health professionals should ensure that we remain patient focused and grounded on core clinical needs. This is an exciting vision for all our futures.

To your second question… Brexit comes ever more rapidly over the horizon and is increasingly a matter of concern – not only for the UK but also in the wider European medical community. In the absence of detail and political guidance, it is extremely difficult to make definitive remarks. At present, therefore, I prefer to avoid speculation in this regard. That said, I have enormous faith in the community of rheumatologists and HPRs working across the continent and within the EULAR family. I see only a continuous and harmonious mutual desire to improve the outcome for people with RMDs. I believe that Brexit will make little difference to this in the long term, and am determined to defend this ambition to the utmost of my ability.

**EULAR** will soon develop a new strategic plan. What issues do you think it needs to address? What direction of travel do you foresee for EULAR generally and the HPRs within that?

One of our priorities in the next 12 months is to revisit the EULAR strategic plan. Given the enormous successes delivered by the organisation in the last five years, it is likely that this will be a progressive rather than rewritten document. The direction of travel will probably be determined by the community rather than by individuals and, as such, my views are “but one voice”. Priorities, I suspect, will be to deliver on the possibilities of the digital revolution as e-health becomes an increasing reality. Capitalising on the molecular biological age will be critical for our patients as precision / high definition medicine rolls out across our discipline.

Meantime we must continue to ensure access to care across Europe, recognising the rather diverse healthcare economies that exist. Finally, the needs of people with RMDs should be felt prominently and regularly in the highest offices across Europe – both at the national and transnational level. EULAR will be fundamental and essential to achieving these ambitions. HPRs are a core part of the EULAR community and will participate as welcome and essential partners.
EULAR 2017 Congress highlights

Jette Primdahl from Denmark and Ricardo Ferreira from Portugal had the honour of delivering highlights from the health professional in rheumatology (HPR) programme at the close of the Annual Congress of Rheumatology EULAR 2017 in Madrid. Here, they come together to share with you their high spots from an active and engaging congress.

Three of EULAR HPR’s founding members – Vicky Stephenson, Angelika Kruse-Jensen and Ulla Nordenskiöld – were honoured guests at this year’s congress. Attending for the first time in decades, these pioneers share their reflections on their experience and how far HPRs have come in their 30 years.

Several presentations by health professionals in rheumatology (HPRs) at EULAR 2017 highlighted the important contributions from HPRs. In this article, we try to share some of them.

Bergsten U. (SAT0725-HPR) demonstrated that a nurse-led, tight control clinic for patients (n=70) with rheumatoid arthritis (RA) with moderate/high disease activity achieved similar improvement in DAS28 and may be as effective as usual care. Most previous randomised controlled trials (RCTs) have studied only patients with low disease activity (LDA).

De Thurah A. (THU0657) had conducted a RCT with RA patients in remission or LDA (n=294), where a patient reported outcome (PRO)-based telehealth follow-up strategy for tight control performed by rheumatologists or by rheumatology nurses was compared to conventional outpatient follow-up by physicians. The three groups presented similar disease activity control and satisfaction after 52 weeks.

Björk M. (OP0143) focused on the need for increased awareness of patients’ foot problems, which is experienced by 80% of patients with RA, and leads to restrictions in participation (daily life, work ability, leisure activity, etc) and can be an early sign of RA. Further Björk M. (SP0041) focused on the current needs for rehabilitation, as disability remains a key problem for many patients despite new pharmacological treatments. Patients still perceive high disease impact, namely on pain, fatigue and function.

Hewlett S. (OP0139-HPR) specifically addressed fatigue. Cognitive behaviour therapy delivered by pairs of rheumatology nurses and occupational therapists (OTs) can significantly reduce fatigue in patients with RA. The intervention in their RCT (n=308) consisted of usual care plus 6 weekly 2-hour group sessions and a consolidation session (week 14), helping patients make links between thoughts, feelings and behaviours, with daily diaries of energy expenditure and weekly goal-setting.

Prevention is another key area for HPRs. Goulonok T. (OP0066) revealed that a nurse-led vaccination programme dramatically improved pneumococcal vaccination coverage (from 17.1% to 77.6%) among 126 consecutive adult patients with chronic inflammatory rheumatic disease (IRD) admitted in a hospital day unit in France.

Dagfinrud H. (SP0089) presented evidence that high intensity exercise is safe in patients with active rheumatic disease. Furthermore, high intensity exercise can contribute to a reduction in disease activity as well as an increase in cardiorespiratory fitness. Thus it can help reduce the risk for cardiovascular diseases. In addition, based on an RCT (n=126), Rooij M. (SP0090) demonstrated that tailored exercise therapy for patients with knee osteoarthritis (OA) and with severe comorbidity (for example, cardiac disease, diabetes type 2, COPD, obesity) is effective and safe. The results may help to prevent both therapists and patients from reducing exercise intensity to a level unlikely to be effective due to their fear of aggravating symptoms.

Lange E. (OP0258-HPR) presented another person-centred RCT (n=74) with very positive results of an intensive progressive aerobic and resistance exercise programme for elderly people (mean age (SD)=70 (2.5) years) with RA. The intervention consisted of a 20-week individual programme, 3 times a week, guided by a physiotherapist. The control group followed a home exercise programme twice a week. All participants in the intervention group completed the study and significant improvements were found for VO2 max, the Chair Stands test, the Timed up and Go, bicycle endurance test and SF36-physical when compared to the control group.

Prior Y. (SP0043) reported a feasibility RCT (n=55) investigating short-term (9 months) effect of an OT-led vocational rehabilitation programme in people with inflammatory arthritis where 28-40% become work disabled within 5 years after diagnosis. The programme was acceptable for the patients and indicated that the programme may reduce presenteeism, and improve symptoms and health status.

Redmond A. (SP0139) gave a brilliant presentation regarding the benefits of patient engagement in research and shared the very positive experiences from Leeds regarding the involvement of patients in research. It gave great inspiration to all HPRs.

You can access the abstract archive at [http://scientific.sparx-ip.net/archiveeular/?view=2&c=s](http://scientific.sparx-ip.net/archiveeular/?view=2&c=s) On-demand, online access to the EULAR 2017 congress recorded educational sessions is now available for a fee from [http://congress.eular.org/eular_2017_recorded_sessions.cfm](http://congress.eular.org/eular_2017_recorded_sessions.cfm)
Ricardo Ferreira, RN PhD candidate, is a nurse researcher at the Rheumatology Department of the Centro Hospitalar e Universitário de Coimbra, Portugal. His research focuses on exploring whether patient reported outcomes could be used as a guide for personalised medicine in rheumatoid arthritis.

Jette Primdahl, associate professor, PhD, RN, is a nurse researcher at the University of Southern Denmark, Hospital of Southern Jutland and King Christian X's Hospital for Rheumatic Diseases, Denmark. Her research focuses on patients with inflammatory arthritis, the nurses’ role, nursing consultations, the patients’ perspective on their disease, and changes in healthcare provision and how this affects the patients clinically.

Ulla Nordenskiöld
EULAR Meritorious Award winner and retired occupational therapist living in Sweden

It was fantastic and inspiring to meet all old and young colleagues again. My warm thanks to EULAR for inviting Vicky, Angelika and myself. I was also greatly honoured by my nomination for the 2017 Meritorious Award.

I found accessible and interesting networking among colleagues from different countries in the EULAR Village. The number of submitted abstracts has increased since I was involved – 323 important abstracts by health professionals, with both research and practical clinic observations. And with over 14,000 participants from 130 countries, the congress was enormous! Hopefully this will lead to patients in Europe having as good a rehabilitation as possible. This has always been the goal for EULAR.

I would like to congratulate the previous HPR Vice President Christina Opava for her four successful years. In Barcelona in 2007, only four countries had an HPR association member. Now there are 25 countries!

Finally, I congratulate new Vice President Tanja Stamm and quote her: “that rheumatology should become the most attractive area for HPRs to work in.”

Vicky Stephenson
Retired rheumatology specialist nurse living in the UK

How great it was to meet up with Angelika and Ulla after so long, and rekindle feelings of friendship which were born from a common desire to enable HPRs to come together and share knowledge and experiences to improve the holistic care of people battling rheumatic disease. I felt the years roll away as memories flooded back.

Congress 2017 was very exciting and almost overwhelming due to the scale and complexity of the event. How things have changed! The HPR sessions were all encompassing and there was something for everyone to learn and enjoy. The poster sessions displayed a high level of professionalism which made me realise just how far HPR delegates have advanced during the last 30 years.

Great credit is due to those who have steered the organisation to where it is today and my very best wishes go to new Vice President Tanja Stamm and her team. My thanks to all concerned in enabling me to have the experience of Madrid.

Angelika Kruse-Jensen
Retired chief pharmacist living in Norway

Thank you all for a wonderful celebration of EULAR’s 70th anniversary and HPR’s 30th anniversary. The committee ensured that it was a joy to experience the professional as well as the social part of the programme. I am particularly grateful for being commemorated for the efforts we started in Athens in 1987.

While it was sad that Willy Peeters and Ingrid Due Pedersen could not be with us, it was a delight to see Ulla and Vicky after all these years. It brought back memories from our own establishment of Allied Health Professionals (AHP), and I was moved to be with them again at the EULAR Congress.

In 1987, most congress participants were doctors. This year, it was good to see the wide array of health professionals participating. Interesting projects and new research were presented in a professional and engaging manner, with the shared focus among the professions on the patient as a common denominator.

The 2017 Madrid congress highlighted how representatives from medicine, pharmacy, healthcare, dentistry, and social services can cooperate and share high-level research results.
Sharing expertise

The EULAR mentor programme for health professionals in rheumatology (HPR) continues to grow as people sign up to become mentees and mentors. Here, two HPRs help explain how it could be of benefit to you.

Jo Adams, UK, the programme founding leader, provides an overview

For many health professionals working with patients with rheumatic and musculoskeletal diseases (RMDs), getting involved with academic clinical projects is a great start to understanding which clinical services and approaches are the most effective for patients.

However, for people new to clinical research it can be that the skills needed to get engaged with research are new. This is where the EULAR health professional academic mentorship programme aims to support and share the impressive clinical academic research expertise that has been developed with the EULAR community.

“We are lucky to have many eminent world-leading HPRs”

EULAR’s academic mentorship programme has been in existence since 2013. It has 20 experienced health professionals across Europe who have been supporting 17 health professional mentees in developing their clinical academic skills and providing support to get involved with clinical research in their own country in the rheumatic and musculoskeletal diseases field.

We are incredibly lucky to have many eminent world-leading health professionals who are keen to support others to develop academic skills that can help them explore and develop the services they offer to their own patients in their own country.

Having accessible and supportive help from a more experienced academic mentor can be a tremendous help at the start of undertaking research. We are fortunate to work with some generous, committed and experienced academic health professionals who have been keen to support others in getting involved in research.

Hana Šmucrová, Czech Republic, is a mentee. She explains how she values the programme

It is fantastic that EULAR had the idea to prepare this kind of programme for health professionals working in rheumatology. I believe it is developing into an excellent resource.

One of the key aims of EULAR is to increase the quality of education for HPRs. This then later translates into increased quality of life of people with rheumatic and musculoskeletal diseases. This mentorship programme can help fulfil this aim.

I very much appreciate the EULAR activities which exist to support young HPRs in our own clinical and research work. Young HPRs have a unique opportunity to work with colleagues with lots of experience in the clinical and research fields.

“The mentor leads the mentee in every step of the process”

A mentor can give lots of valuable advice on how to start on a research project and the other things connected to the research work. For example, offering mentoring on how to write an abstract, poster or oral presentation. The mentor leads the mentee in every step of the process.

Because of evidence based medicine and evidence based therapy, research in the field of HPRs is more and more important these days. Via this mentorship programme, HPRs can start their own research activities.

I signed up to be a mentee on the programme. My first step was to have a Skype call with Jo Adams, the programme lead, where we discussed the suitability of the project for me. Later, Jo put me in contact with Sofia Barbosa Boucas who became my mentor. I had a Skype call with Sofia and she explained to me how to go about researching the project I had in mind – and she kindly helped me to start searching the literature that is necessary for the project.

To find out more about the programme or to take part, contact Annette de Thurah at annethur@rm.dk

Hana Šmucrová, right, in action chairing an HPR session with Andrea Domján from Hungary
This current issue of EULAR HPR News concentrates on the issues behind the new EULAR campaign Don’t Delay, Connect Today. The campaign focuses on early diagnosis and how it can prevent rheumatic and musculoskeletal diseases (RMDs) causing irreversible damage to the body. However, regardless of our knowledge about the importance of early diagnosis, we also know that achieving it is often far from real life for patients with RMDs, and we need to do better!

Why the delay?

Joint problems are a very common symptom in the general population, and can be caused by many other conditions than RMDs. This is one of the things making early diagnosis difficult. It is generally believed that people often do not go to health professionals (HPs) and doctors as soon as symptoms appear because society in general does not place sufficient value on joint care. We also know that many HPs feel unconfident about their skills regarding detection of symptoms. In other words, delay in treatment is caused by problems across all parts of the patient pathway. First, it is difficult for patients to identify symptoms and, thus, the exact time of the onset of symptoms. Diagnosis can further be delayed due to a time lag from symptom onset to the patient choosing to consult an HP or doctor. Finally, there can be a time lag from referral from the HP/doctor to the rheumatologist for final diagnosis and start of treatment. This makes the problems with early diagnosis complex and raises the importance of awareness.

The role of health professionals in rheumatology

It is generally viewed that frontline HPs (for example, community nurses and physiotherapists) could have a potentially important role in recognising the signs of RMDs and, thus, in facilitating early diagnosis. Among other things, HPs can help patients distinguish between, for example, signs indicating osteoarthritis and inflammatory arthritis, and guide them accordingly. When relevant, health professionals can also give advice to patient groups on behavioural changes in the early stages that can, potentially, optimise function and minimise disability.

In years to come we can expect an increase in the number of patients living with RMDs due to the change in demography. This will challenge healthcare systems and require new models of care that will include HPs. In Switzerland, so-called Urban Walk-In-Clinics run by advanced nurse practitioners have been introduced. Based on the idea that well-educated HPs can pick up warning signs from patients, these clinics can serve as a new model in primary care (Kambli K, et al, 2017). To make this a success, proper HP education and skills will, however, become increasingly important and, hence, we must draw on all our efforts at EULAR to prepare the HPR workforce for these new tasks.

Promote the campaign

All EULAR HPR members are encouraged to take part in the campaign by organising or collaborating on local activities or events, and many countries have already picked up this challenge.

To support these activities, EULAR has made information available on the campaign website (eular.org/what_we_do_dont_delay_connect_today.cfm). Here, you can find an overview of the Don’t Delay, Connect Today campaign, and information on how to plan local campaign activities or events. You can also find key guidance, templates and artwork for your use, and materials to help you support the campaign. Among other things, you can also find a special toolkit, targeted specifically at HPRs.

The aim of Don’t Delay, Connect Today is to create awareness of the importance of early diagnosis in RMDs. Its success is very much dependant on this message spreading all over Europe. Therefore, it is my hope that EULAR HPR membership countries will accept this challenge of creating national campaigns together with medical doctors and patients. Don’t delay – get started today!
Influencing health research and innovation

Neil Betteridge, EULAR Liaison Officer, Public Affairs, reports on developments during 2017

As readers of HPR News will already be aware, one of the main topics EULAR has prioritised for its public affairs activity during 2017 is research and innovation. The EU is currently running its mid-term evaluation of Horizon 2020, the current Research Framework Programme. Indeed, it has already started to discuss the next 7-year research programme which will start in 2021.

All of which means that this is the right period to be discussing with policy makers and stakeholders how the new EU research policies should be developed and implemented going forward. From EULAR’s perspective, it is of course also the right period to be presenting the views, recommendations and calls to action of the rheumatic and musculoskeletal disease (RMD) community, including the specific perspective of EULAR’s Health Professional in Rheumatology (HPR) network.

Launch of RheumaMap

With this in mind, it was in May 2017 that EULAR launched its own vision of rheumatology research for the longer term, RheumaMap, in the European Parliament. The launch took place during one of the meetings of the MEP European Parliament Interest Group on RMDs. EULAR has provided the secretariat to this group since 2009 and important, highly constructive relationships have continued to be built over time.

The title of the meeting was “Fostering medical research excellence in Europe”. Its aim was to discuss the future of health research in Europe and to present and discuss the main challenges in research and innovation in RMDs. The current President of EULAR, Prof. Johannes Bijlsma, presented RheumaMap, and other speakers included representatives of the European Commission, the Innovative Medicines Initiative (IMI) and the Alliance of Biomedical Research in Europe, of which EULAR is a member.

To maintain the focus on this topic, EULAR opted this year to organise our annual World Arthritis Day conference on “The future of health research and innovation after Horizon 2020. Do we need a novel approach?”. The aim was to build on the discussion held in May and to discuss the main challenges in health research and innovation in Europe, including the role of EU institutions and Member States in fostering medical research.

I am delighted to report that around 120 persons attended the event, including high level representatives of EU institutions and stakeholder organisations.

Addressing the key issues

Keynote speeches addressed exactly these issues – the main challenges in European medical research and innovation, and how to prioritise research and innovation efforts, with rheumatology the exemplar discipline. More specifically, the conference produced concrete policy recommendations as to what EU and national policy makers – but also the wider community of stakeholders – could do on key issues.

Workshops were held on the next EU research framework programme; the implementation of public-private partnerships in research and innovation; the engagement of patients in research and innovation; and on the challenges involved in the transfer of research findings and innovations into clinical practice. The last workshop specifically addressed the challenges of HPRs in transferring research and innovation developments into their clinical practice.

Access to medicines

But, of course, other topics on our public affairs agenda have also been pursued by EULAR in this last period, and addressed by Members of the Interest Group on RMDs. A meeting of the group that took place on 11 October, for example, focused on “Improving access to medicines for European citizens”. Access to medicines is a serious problem – in certain European countries especially. We have direct experiences of this in the RMD community of course, such as poor availability of certain treatments, including restrictions for the reimbursement of biological therapies. The aim of the meeting, therefore, was to discuss with MEPs, the European Commission and stakeholders how the EU can help to solve these issues, and how health professionals, including HPRs, can contribute to greater patient access to treatments.

The next meeting of the Interest Group will address disability policies. The EULAR HPR community will, once more, be well placed to provide significant input.

On behalf of EULAR, I remain hugely appreciative of the contribution to our advocacy activities made by our HPRs. We simply could not achieve all that we have realised so far without your engagement and commitment. Thank you.
Do you know your neighbours?

Nele Caeyers, Chair of the Standing Committee of PARE, explores the potential for closer collaboration between EULAR’s PARE and HPR member organisations

Don’t Delay, Connect Today: this could be a strong message for the national EULAR member organisations of Health Professionals in Rheumatology (HPR) and PARE. By joining forces at the national level, our common goal of improving the lives of people living with rheumatic and musculoskeletal diseases (RMDs) could get a real boost.

Within EULAR, all three pillars strive for the best possible care for people with RMDs. All of them are successful in their work. Over the past years, we have made progress and seen improvements at different levels. But we are not there yet!

Is there a need to “connect” even more? On a European level, HPR and PARE have a strong relationship. We can proudly say we have tight connections and work well together on many different projects. But what about at the national level? Both HPR and PARE were eager to learn about the level of collaboration between these two EULAR pillars in the different European countries. So, we co-developed a specific survey for both groups and I want to thank the EULAR HPR and PARE member organisations for taking the time to fill in the survey and letting us know their thoughts and ideas. We learned a great deal and it is my pleasure to share some of the feedback with you here.

The majority of HPR associations do work together with their PARE equivalents in their country or are interested in doing so. At national conferences, the two pillars make sure there is representation so all voices can be heard. HPR and PARE organisations work together on patient education and, in a number of countries, also on ensuring that patient involvement in developing guidelines or recommendations gets the necessary attention.

As PARE, we are happy to see that World Arthritis Day, every year on 12 October, has offered – and will continue to offer – many opportunities for joining forces. The feedback told us that materials offered by EULAR, like toolkits with printing materials, make it easy to launch a campaign at national level. It is great to see these ideas are used and enhance the collaboration between HPR and PARE. Also, the recent EULAR campaign Don’t Delay, Connect Today is being picked up in several countries. The successful start of the campaign in the Atocha train station in Madrid will get some spin offs all over Europe. Those organisations that responded to the survey clearly said that they want EULAR to continue with these kind of joint initiatives as it helps the different pillars come together naturally.

“Time is the biggest hurdle”

As for barriers that stand in the way of good collaboration, time is the biggest hurdle. Everyone is busy, of course, and putting more people around a meeting table might give the impression of consuming more time. In the end, though, quality can really be improved. So, give it a second thought when you look at your agenda and decide to skip the call with your national PARE member. People with RMDs want to join forces and improve their skills to be better advocates for the large group of people they represent. Mutual understanding can only improve the way both groups work and will result in more awareness and better care in the end.

In conclusion, the survey showed that there is a great deal of good will and a wish to work together more closely at a national level as well as on EULAR projects. The first EULAR joint campaign Don’t Delay, Connect Today is already proving to be a good way of getting national associations together. From this, even stronger collaborations can grow in the future. From the PARE side, we surely want to support this.

EULAR can help us in sharing best practices, but people also expressed a wish for easy access to up to date contact details. Perhaps there might be the opportunity to support educational visits between EULAR member organisations of the two pillars in the future. We are sure the pillars can learn from and inspire each other. In the end, we all benefit from that. So, let’s #ConnectToday!
Poor sleep has been identified as a major concern for people with rheumatoid arthritis (RA), with disturbed sleep and fatigue known to affect up to 70% in this population. This, consequently, has an effect on patients’ quality of life, in addition to their mental and physical health. It may also lead to people with RA not being as physically active as their healthier counterparts.

Sleep is an important aspect in maintaining the body’s circadian rhythm, and is an important factor that influences mood, physical and cognitive performance, and daytime sleepiness. In general, getting fewer than five hours sleep per day has been associated with cardiovascular issues, diabetes and obesity. It can also be linked to depression, anxiety and poor productivity, with sleep debt representing an ever-growing epidemic in western modern society.

Rigshospitalet, in Copenhagen, has been researching the area of sleep for many years and has one of the best centres in the world. It also has the benefit of having their rheumatology research centre co-located in the same building.

Through attending and presenting at EULAR congresses in Rome and London, I was able to meet with Dr. Bente Appel Esbensen who is associate professor and senior researcher at the Centre of Rheumatology and Spine Diseases (VRR), located at the hospital. Out of these meetings, a visit to the centre was arranged and was supported by a EULAR HPR educational grant.

Aims of the visit

The visit took place from 14-17 March 2017 which meant I was able to enjoy the Saint Patrick’s Day celebrations outside of Ireland! The aim of my educational visit to Rigshospitalet was multifaceted.

Firstly, the grant provided me with the opportunity to finalise a trial for Phase II of my PHD, which is a pilot/feasibility RCT of an exercise programme versus exercise advice for people with rheumatoid arthritis (RA). Outcome measures being sleep and aspects of mood. The visit facilitated discussion and collaboration regarding the methodology, in particular the outcomes to be used, proposed data analysis and writing up of the intervention protocol.

Dr. Appel Esbensen’s research centre is comprised of research, clinical and educational programmes geared to advance the field of sleep and improve patient care. Her centre has driven considerable growth in sleep research and treatment in people who have RA. It was fascinating to see how their research units operate and I was really appreciative of the time given up by the staff of COPECARE, DANBIO and REU-STOP.

Secondly, a visit to the Department of Clinical Neurophysiology, under Prof. Poul Jennum was combined with Dr. Appel Esbensen’s department. Prof. Jennum’s department is specifically responsible for the Danish Centre for Sleep Medicine at the University of Copenhagen, Rigshospitalet. Because sleep encompasses some of the greatest remaining mysteries in the biological sciences, breakthroughs in this area will constitute some of the foremost advances in human health. This visit helped me gain new knowledge and refine my intervention design through collaboration with both departments.
standard for assessing total sleep time (TST) and sleep quality is polysomnography (PSG), and seeing how this is used in practice was invaluable.

Thirdly, the educational visit allowed me to build on, and further develop, a research partnership, which is in its relative infancy, between the University of Limerick and the research group at Rigshospitalet. This Danish group has undertaken a number of large, multi-centre interventions in connection with sleep and increasing physical activity levels in people who have RA. Thus, the final aim of the visit was to develop my knowledge around the development and delivery of a large, multi-centre intervention for people with rheumatoid arthritis. Additionally, the visit has informed me of the translation of such research projects into clinical practice and the practical issues surrounding this knowledge translation.

The research visit has ultimately lead to a collaboration with the established, highly regarded and research-active Rigshospitalet group, which identifies strongly with the collaborative research projects that EULAR supports.

Positive benefits

Health professionals in rheumatology (HPRs) should also benefit from this visit as I have learnt about the evidence emerging from the Danish group on the effectiveness of exercise in sleep in people with RA. This will influence the choice of outcome measure in both research and clinical practice, ensuring reliable and valid measurements are used in improving sleep quality in people with RA.

The visit has allowed me to transfer new knowledge around the research being conducted in Denmark to clinical practice in Ireland. This new knowledge will incorporate the development and implementation of my PhD exercise intervention to increase physical activity levels and exercise in people with rheumatoid arthritis. I plan to transfer this new knowledge to HPRs working in the area of rheumatology via a presentation to the Irish Society of Chartered Physiotherapists Clinical Interest Group in Rheumatology (CPR) and the Irish Health Professionals in Rheumatology (IRHPS). This will ensure that the new information is provided directly to HPRs specialising in the management of people with rheumatic and musculoskeletal diseases (RMDs).

Involving people with RMDs in research

While the educational visit will not provide initial direct benefit to people with RMDs, through their ultimate involvement in my study it is hoped that valuable data will be collected about the impact of exercise in people with RA from a sleep perspective. The collaboration between patients and health professionals in research is relatively new. Patient participation ensures better representation of their needs and uncertainties, helps prevent any mismatch between their preferences and the scientific focus of any research. In addition, it may result in their empowerment and enhance their sense of ownership.

The study recognises the involvement of patients with a view to contributing empirical evidence that the involvement of public and patients in research is associated with improved outcomes and translation to practice. This is advocated by the EULAR recommendations for the inclusion of two patient representatives in scientific projects. The study protocol is presently under review with a journal and we are very appreciative that Dr. Appel Esbensen is also one of the authors.

Applying for a grant

EULAR awards up to 10 bursaries per year for educational visits. They are for health professionals working in the field of rheumatology to enable them to visit colleagues in other countries. Information about how to apply can be found on the EULAR website at www.eular.org/health_professionals_educational_visits.cfm

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

Apply for a grant
FOR-RHeUMA

By Marco Testa of the Italian Forum of Health Professionals in Rheumatology

FOR-RHeUMA is a non-profit organisation for health professionals working in rheumatology (HPR) in Italy. It is dedicated to the development and co-ordination of action to fight against all rheumatic and musculoskeletal diseases (RMDs). It was created in May 2016 for non-medical health professionals who work in care, prevention, accompaniment, research, survey, learning and training.

FOR-RHeUMA takes action – especially about the medical, psychological and social consequences of RMDs. Our association is open to professionals from all health-related professions directly or indirectly involved in the care and prevention of RMDs. Health professional members might be nurses, occupational therapists, physiotherapists, psychologists and psychotherapists, and podiatrists. FOR-RHeUMA is also open to effective collaboration from professionals not involved in the health system, like architects, philosophers, urbanists, physical education teachers – people who can also bring a useful contribution to the wellbeing of people with RMDs.

Since our launch, our main activity has been to develop a strategy to increase our visibility and recruit new members. We have networked with other profession-specific associations such as the Italian Association for Physiotherapists (AIFI) and the Italian Association for Occupational Therapists (AITO), and with medical associations, in particular the Italian Society of Rheumatology (SIR). Indeed, FOR-RHeUMA is the only HP organisation in Italy in the RMD field which is supported by the Italian Society of Rheumatology and we have collaborated on the development of a physiotherapist course that was offered at the SIR annual national congress.

FOR-RHeUMA is a new association with a great responsibility, both at national and international level. Our EULAR HPR membership was accepted at the congress in Madrid in June this year. We are proud of this recognition and intend to work hard to repay the trust our European colleagues have put in our association.

Our future challenges include the recruitment of new members, the development of our website (www.4rheuma.org) as mean of dissemination of information and professional knowledge to our members, and to participate in national rheumatology events and conferences to share scientific communication.

Last, but not least, we intend to develop a firm and close collaboration with the Italian patient association to disseminate the message of the need for early diagnosis of RMDs. We will adopt the tools made available by EULAR for the Don’t Delay, Connect Today campaign. With this in mind, an educational project is currently under development in collaboration with the group of the Master in Rehabilitation of Musculoskeletal Disorder of the University of Genova – Campus of Savona.
Croatian association of healthcare professionals in rheumatology and rehabilitation – LABUD

By Branka Rimac, President of LABUD

Discussions about joining the EULAR Health Professionals in Rheumatology (HPR) were held with EULAR over a number of years. We had certain challenges. In the Republic of Croatia there are several health professional associations – so physiotherapists and nurses have their own associations for example. A joint association, bringing together healthcare professionals who care about a particular population or disease did not exist and there was no experience of this model.

The national associations of nurses and physiotherapists strive for their members but were afraid of members fleeing to a new association. It was necessary to overcome their fears and much time has been spent reconciling all the nurses and physiotherapists. The other groups had no similar problems as there are only a few NGOs.

For a long time, the nurses’ association obstructed our progress by refusing to allow members to join a new association. They were worried the nurses’ “parent” society would suffer fewer members, lower membership fees and fewer companies listed as working in the Croatian Association of Nurses. The establishment of a new multi-professional association did not pose a challenge to physiotherapists – perhaps because there is a smaller number of physiotherapists than nurses in the Republic of Croatia and there are several physiotherapist associations.

Christina Opava, the former EULAR Vice President representing health professionals, helped us overcome some of these professional challenges when she attended our 28th educational course. She gave a lot of confidence to attendees and gained support for the EULAR HPR network from the membership.

This gave us the basis for founding the Croatian Association of Health Professionals in Rheumatology and Rehabilitation known as LABUD. The prospect of representing EULAR and HPRs, and opportunities for co-operating with other members, reinvigorated people who had advocated this idea for years and they started fulfilling the required EULAR membership requirements.

The EULAR General Assembly accepted LABUD’s plan and programme. This includes developing guidelines for specific areas of expertise in rheumatology and rehabilitation, promoting training, designing and implementing lifelong learning programmes, CPD, and creating and managing projects that are important for the health information of the population. We were ratified as members in June. Unfortunately, we were not able to attend the ceremony in Madrid, but we felt great pleasure in becoming members.

As LABUD’s newly-elected President, I have thanked the former President, Vesna Barbarić, and Secretary, Julijana Tenodi Maraković, for their efforts in founding the association. Julijana remains as Secretary. I have highlighted the importance of enrolling new members to strengthen LABUD and establish us as an important organisation. We must participate in developing strategies for the education of health professionals, and in promotional and educations campaigns about maintaining mobility.

As HPRs, we have great challenges ahead – especially when we consider the growing number of people affected by RMDs and illnesses of the locomotor system caused partly by a new way of life (too little movement, plenty of seating, few daily activities).

Therefore, as an association of health professionals consisting of nurses, physiotherapists, psychologists, work therapists and nutritionists, there is an important task ahead to teach people of all ages that exercising for 20 minutes a day is as important as brushing teeth.

At the same time, all our HPRs are encouraging colleagues to affiliate to the association and this will be a great challenge!

EULAR Health Professional Membership Directory

EULAR’s Directory of Health Professional Member Organisations 2016-2017 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.

Visit eular.org/health_professionals_member_orgs.cfm to view or download your copy of the directory.
EULAR HPR Study Group reports

The EULAR HPR Study Groups (SGs) met face to face at the EULAR 2017 Annual European Congress of Rheumatology in Madrid. Here, the Study Group leaders provide their feedback

EULAR Physical Activity and Exercise Therapy Study Group

By Rikke Helen Moe, Study Group Lead, and Li Alemo Munters, co-Leader

We are a multidisciplinary research group with physical activity and exercise therapy as our special interest. This was our first meeting as the new SG. We work systematically for high quality assessments, recommendations and implementation of physical activity and exercise therapy for persons with RMDs. Furthermore, we facilitate, support and initiate clinical development, research projects, assessments and session proposals.

We have two ongoing projects. At the meeting, we received an update on the EULAR recommendations / points to consider for physical activity. Karin Niedermann, Thea Vliet Vlieland, Norelee Kennedy, Hanne Dagfinrud and others have started to work on the recommendations that will include both inflammatory arthritis and osteoarthritis. Also, we received an update on our second project. Nina Brodin reported that the “Physical Activity and Aerobic Capacity Assessment – a Survey among Patients and Health Professionals in Sweden, Ireland, Denmark and Belgium” project is now waiting for publication. Furthermore, she also reported on the “SQUASH”, a questionnaire assessing physical activity that has been translated and used in Sweden, Denmark and Norway (Wendel-Vos GCV, Schuit AJ, Saris WHM, Kromhout D. Reproducibility and relative validity of the short questionnaire to assess health-enhancing physical activity. Journal of Clinical Epidemiology. 2003;56(12):1163–9). Members interested in taking part in the translation and cultural adaptation of the SQUASH were asked to contact the SG leader.


Our SG will continue to work on two proposals for sessions for the EULAR 2018 congress programme.

Finally, we congratulated Alison Hammond, UK, who received this year’s research grant.

Foot and Ankle Study Group

By Dr. Gabriel Gijon-Noguere, Study Group Lead

The 5th meeting of the Foot and Ankle Study Group (SG) was held at the EULAR Congress in Madrid and welcomed three new members. We hold quarterly virtual meetings using video conference, but this is our only meeting in person.

First of all, we thanked Dr. Begonya Alcacer-Pitarch as she stepped down as a convener. She had co-led the SG since Paris in 2014 and, now, I will be the sole convener. My four-year term will end next year as there will be an election in Amsterdam for a new convener.

We discussed future research projects for studies we are conducting and identified areas for development. One of the main projects we are currently undertaking is “ Provision of Care Services for Rheumatic and Musculoskeletal Disease-Related Foot and Ankle Problems: A Survey from 16 European Countries”. This programme of work is being led by Dr. Begonya Alcacer-Pitarch (University of Leeds, UK) and we are waiting to publish this project later this year. Given the success of the project, it was unanimously agreed that the second phase should progress – to translate and validate the PRO questionnaire for patients with RMDs in the different languages of European countries. Furthermore, the group is currently working towards developing the study design, securing funding to undertake the study and identifying collaborators from the different EU countries.

Full details will be circulated to those on the group’s email list. Anyone who would like to join the group or would like further information should contact me at gagijon@uma.es

Nurses Study Group for Research and Strategy (REST)

By Yvonne van Eijk-Hustings, Study Group Lead

Approximately 20 rheumatology nurses (nurse practitioners and specialised nurses), and 1 rheumatologist from various countries attended the meeting in Madrid. Discussion was hampered as some attendees entered late (having attended the STOPe SG which was scheduled to finish as our meeting started at the opposite side of the congress centre) and others left early (because of the Congress Dinner).

REST has already succeeded in its aim to provide a platform for international collaboration in research. This has been displayed by the various international projects that have been finalised and published (Fusama M, et al. Mod Rheumatol 2016. Hammes B, et al. BMC Med Ethics 2016, Prindahl J, et al. Musculoskeletal Care 2016), and by two on-going projects with upcoming output (Minnock P, et al, revision submitted) and van der Elst K, et al. (to be submitted).

The current state of the latter and following steps were presented. Also, new participants attended and connected with others for future research.

The discussion on last year’s research agenda resulted in a proposal for a joint project: exploring changes in the development of extended roles in Europe by repeating (part of) the survey on HPR roles, presented in London 2011. However, the context of nursing care differs widely across Europe, therefore, we will need detailed descriptions of this in order to understand data from the survey. This study will result in a publication. A multinational working group has already been formed and work will start in the next months, with a report given during the 2018 SG meeting.
**Study group on Patient Education (STOPE)**

**By Mwidimi Ndosi, Study Group Lead**

The EULAR SG on Patient Education (STOPE) aims to: (i) promote excellence in patient education research (ii) disseminate research evidence (iii) support implementation of EULAR recommendations that have a patient education approach and (iv) promote collaboration among professionals and patients interested in patient education across Europe.

This was the second face-to-face meeting after the SG launched at the 2016 EULAR Congress in London. This year’s meeting was attended by 21 members from 11 countries. The current membership is 51 – with 5 professions and patients representing 15 countries. See figure 1 (below). The meeting aimed to discuss work done since last year and lay out our priorities for the next.

Members were made aware of progress in the translation of the EULAR recommendations for patient education, which are now in 10 languages: Danish, Dutch, Finnish, French, German and Swiss German, Japanese, Norwegian, Polish, Spanish and Swedish. Work is still in progress on the Portuguese translation.

Two priorities for this year were outlined: (i) to translate the lay summary of the recommendations and (ii) disseminate and evaluate the recommendations using national surveys. For the translation, members were asked to use the “dual-panel” approach and an example was given on how this is done. Two examples of dissemination work were presented, one done in Sweden by Dr. Carina Bostrom and the other one in Switzerland by Dr. Karin Niedermann.

A survey is being developed by myself and Dr. Heidi Zangi, and this will be distributed electronically to all country champions who will translate it into their respective languages. The survey will help to disseminate and evaluate the recommendations among HPRs in Europe.

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**CLINICAL NURSE STUDY GROUP 2017**

**By Jenny de la Torre-Aboki, Study Group Lead**

14 nurse colleagues from different European countries attended our meeting: Sweden, Denmark, Spain, Netherlands, Slovenia, UK, Norway. No specific working groups have been created, nevertheless networking is still an important activity of the SG.

The following topics were discussed during the meeting.

- Organisation of a research project or specific working group on the topic “How to measure nursing clinical interventions impact?”. This issue is quite wide and perhaps it could begin with a study to understand what nursing clinical intervention is, which clinical interventions should be included, which disease to consider and how nursing intervention impacts on scenarios from quality of life to health economics.

- Nurses are encouraged to send session proposals for the EULAR 2019 Congress in Madrid (sessions are already organised for the 2018 Congress in Amsterdam). Timescales for submitting session proposals will be sent shortly. If you are interested in sending a session proposal and/or you need any help with the process, please contact me at delatorre_jen@gva.es or Yvonne van Eijk-Hustings at yvonne.eijk.hustings@mumc.nl

- Participation with ESNO (European Specialist Nurses Organisation):
  - to create a leaflet specific to nurses to improve information regarding biosimilars, ESNO would like to invite nurses willing to review written information and return their feedback.
  - at the moment EULAR is collaborating with ESNO in the development of a rheumatology nurses’ competences framework and European qualification. If any nurse is willing to participate or would like to have more information related to ESNO, please contact Yvonne or Jette Primdahl at jprimdahl@gigtforeningen.dk

If you have any questions about the meeting or are willing to participate in any of the activities, please email me at delatorre_jen@gva.es

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For more information about EULAR’s HPR Study Groups, please visit eular.org/health_professionals_study_groups.cfm
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 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
Tanja Stamm: tanja.stamm@meduniwien.ac.at

From June: Slovenia

For contact details, please visit www.eular.org/health_professionals_member_orgs.cfm