The Health Professionals in Rheumatology have much to be proud of since their foundation in 1987

2017 marks the 30th anniversary of the unofficial birth of the Health Professionals in Rheumatology. This issue of EULAR HPR News celebrates the work of your early health professional (HPR) champions and looks at how far the network has come in those decades.

The hard work of HPRs from across Europe drew together people from the range of HPR specialties, all working to share knowledge and experience, and to improve the lives of people living with rheumatic and musculoskeletal diseases.
Get in touch
Welcome to your new-look EULAR HPR News. The newsletter has had a facelift in time to celebrate the 30th anniversary of the Health Professionals in Rheumatology (HPR).

In this issue, EULAR figures from the HPR formative years share their memories of embedding health professionals into EULAR.

Prof. Tanja Stamm introduces herself as EULAR Vice President Elect representing Health Professionals and EULAR President Elect Hans Bijlsma sets out his plans for his upcoming term of office.

Go to page 19 for your quick reference guide to the 2017 EULAR Congress programme and Study Group meeting schedules.

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 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.

Moving EULAR Health Professionals in Rheumatology forward

Incoming Vice President of EULAR representing Health Professionals in Rheumatology, Tanja Stamm, shares her plans for her three-year term of office with HPR News

EULAR has become one of the most important international organisations in terms of leadership in clinical practice and research, as well as in terms of funding and international networking. In my opinion, the co-operation of rheumatologists, rheumatology scientists, patients and rheumatology health professionals within EULAR has contributed importantly to this development.

Rheumatology health professionals (HPRs) deliver excellent work to foster the leadership of EULAR in Europe. As one important aim for my future work with EULAR, I would like to facilitate and encourage this collaboration further through networking of, and support and education for, students and young researchers across disciplines. Rheumatology should become one of the most attractive areas for HPRs to work in – in clinical practice as well as in research. In my opinion, we need more clinical and research projects with HPs being principal investigators.

“We need more clinical and research projects with HPs being principal investigators”

We need to focus on large European grants as well as on current big data initiatives to create better evidence for our interventions and to receive larger funded projects. Accurate measurement of patient reported outcomes, innovative technological innovations and digital assistive devices, as well as studies on the effects of health professionals’ interventions in large samples sizes, will be future research areas.

Furthermore, we need to support networking and the rheumatology careers of health professionals in all European countries. By having a large number of HP member organisations, EULAR is an ideal place to facilitate and drive the future development of health professions on national levels. EULAR’s educational initiatives contribute importantly to an equal educational system for health professionals with comparable competencies in all European countries. Furthermore, I think that we should make efforts to involve currently under represented health professional areas – such as dietetics, clinical pharmacology and social work – much more in the future.

We need to intensify our co-operation, not only with rheumatologists but specifically with patients with rheumatic and musculoskeletal diseases (RMDs). Clinical and research projects should be conducted together with the strong involvement of patient research partners. Close collaboration between patients and health professionals is essential for HPs to deliver the optimal interventions in a well-fitted way. Furthermore, patient centred research will show how health professionals can best benefit people with RMDs.

“Patient centred research will show how HPs can best benefit people with RMDs”

Throughout my experience in international organisations and European projects, I have always appreciated the challenge of working with international colleagues, not only from my own profession but also from other disciplines. From June 2008 to June 2012, I was Chair Elect, Chair and Past Chair of the EULAR Standing Committee of Health Professionals in Rheumatology. Afterwards, I was a member of the Scientific Committee of the European Rheumatology Research Foundation (FOREUM) until 2016. As a professor and occupational therapist working in outcomes research in different medical areas including rheumatology, I highly value the international network of EULAR and I would like to contribute further to it. It is a great honour for me to have the chance taking over this very relevant position for the next three years.
Congratulations to EULAR’s Health Professionals in Rheumatology on your 30th Anniversary!

By Afton L. Hassett, Psy.D., President of the Association of Rheumatology Health Professionals, Associate Research Scientist, University of Michigan, Ann Arbor, MI

Your Association of Rheumatology Health Professionals (ARHP) colleagues are happy for you and proud of all you have achieved. You have built a strong and vibrant organisation and been a friend to ARHP over the years. Memories from the past decade, in particular, highlight the warm relationship between our two organisations.

In 2008, ARHP started hosting the International Rheumatology Health Professional Organisations Networking Luncheon for international attendees of the ACR/ARHP Annual Meeting. Through these meetings, we truly began to appreciate the importance of working with EULAR HPR. Soon after, Karen Kerr, 2007 ARHP President, officially attended the EULAR Congress in Barcelona, Spain. At the invitation of EULAR officers Peter Oesch and John Verhoef, Karen attended the EULAR Allied Health Professionals Standing Committee and Scientific Committee meetings. In turn, as a EULAR representative, Christina Opava attended the 2007 ARHP international networking luncheon in Boston, MA. Since that time, ARHP and EULAR HPR officers have been a consistent presence at each other’s annual meetings.

In 2008, ARHP was invited to contribute articles to EULAR HPR News while, in turn, EULAR members have contributed to the ACR/ARHP’s news magazine The Rheumatologist. Eventually, collaborative activities started to include joint educational presentations. The first occurred in 2012 at the EULAR Congress in Berlin, Germany, where ARHP and EULAR HPR co-presented the session “Promotion of Physical Activity in Rheumatology Targeting Patients, Providers and the Public.”

At the EULAR Congress in Paris, France in 2014, five ARHP members and five EULAR HPR members met to develop new collaboration projects. The result was the establishment of the EULAR Osteoarthritis and Inflammatory Arthritis Pain Task Force, led by Prof. Rinie Geenen. The task force was charged with the development of recommendations for a health professional’s approach to pain management. Funding was secured through a EULAR grant, and two face-to-face meetings were held in Schiphol, Amsterdam. Karen Huisinga and I were included as ARHP members of the task force. Months of careful work resulted in a presentation of findings at the organisations’ respective 2016 annual meetings (London and Washington, DC) and collaboration on a manuscript, currently in preparation.

More importantly, the collaborative relationship is thriving. Officers from EULAR HPR and ARHP meet twice a year during our annual meetings to make plans for future activities. Such endeavours could include collaborative webinars, researcher exchange programmes, mentoring activities and annual meeting sessions. This year we have a joint session entitled “Patient Engagement in Research” to be presented at the EULAR Congress in Madrid, Spain and at the ACR/ARHP Annual Meeting in San Diego, CA. These collaborations serve to benefit our respective members and improve the lives of our patients.

EULAR political engagement and awareness campaign

Promoting the HP perspective in rheumatology to civil society

By Ursula Aring, Communications Manager, EULAR

Starting this year, EULAR is launching Don’t Delay, Connect Today! – a campaign which aims to bring awareness and understanding of rheumatic and musculoskeletal diseases (RMDs) to society at large.

Don’t Delay, Connect Today! has its focus on the urgent need to develop the concept of what EULAR President Prof. Gerd R. Burmester refers to as the “window of opportunity” – the important timings of early diagnosis and early referral of patients affected by RMDs.

Political action in Portugal

Speaking at a roundtable event held at the Portuguese Parliament in Lisbon on 23 February, EULAR Vice President representing Health Professionals, Prof. Christina Opava addressed members of parliament and national media regarding the role of health professionals (HPs) in early diagnosis and treatment.

Recommending a biopsychosocial approach to health, Prof. Opava described the importance of recognising the role of health professionals in rheumatology to the 30-strong audience.

Speaking at the event, she said: “The value health professionals can bring to early diagnosis when acting as intermediaries between doctors and patients is significant. We must promote collaboration and a multi-disciplinary approach in rheumatology and provide continuous education on evidence-based care among the HPR network.”

Campaign into action

The EULAR 2017 Congress and a dedicated publicity stunt at the capital’s main station, Atocha, will kick off the campaign. EULAR member organisations from the three pillars, PARE, HPR and Scientific Committees, are working with the Spanish Society for Rheumatology (SER), the Spanish organisation for health professionals in rheumatology, Openreuma, and the Spanish patient organisation, LIRE. They have joined forces to officially launch Don’t Delay, Connect Today! through events held in June in Madrid.

The campaign itself has been designed to run over the long-term, stretching into 2018 and beyond – with World Arthritis Day in October scheduled to push the campaign pan-Europe.

Taking it local – with a toolkit

National level events are supported using a campaign toolkit designed by EULAR. This provides national associations with guidelines and tools to roll out the campaign at a local level and in local languages. Hana Šmucrová, member of the EULAR HP Educational Sub-committee, said: “The toolkit is the key to bringing great ideas into action and will ensure that all areas of the EULAR network, including HPR, are able to follow the approach. Don’t Delay, Connect Today! It supports mutual co-operation among rheumatologist, health professional and patient organisations at the national and international level.”

www.eular.org

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EULAR PARE Engagement Programme

Yvonne van Eijk-Hustings, senior researcher and rheumatology nurse from the Netherlands, reports on a visit to the Department of Rheumatology, Diakonhjemmet Hospital Oslo/Norwegian Rheumatism Association (NRF) 1-2 November 2016

The main aims of the PARE Engagement Programme visit were to:
1. keep up to date with developments in the biosimilars discussion
2. reach all people with rheumatic and musculoskeletal diseases (RMDs) by connecting with Norwegian member organisations.

On the morning of day one we received a presentation of the key results of the NOR-switch study: non-inferiority of biosimilars but also a prerequisite for research funding.

Following the presentation, the discussion with Prof. Tore Kvien was helpful for updating the EULAR PARE position paper on biosimilars.

In the afternoon we were given a guided tour of the hospital where we saw a number of different facilities.
- Outpatient clinic: patients visit a nurse and/ or rheumatologist for their joint examination and consultation after completion of patient reported outcomes. Results of these PROMs are discussed during the consultation.
- Day care centre: infusion centre. Pre-screening and administrating medication by a nurse.
- Small ward for hospitalised patients.
- Rehabilitation unit for special needs. After a multidisciplinary needs assessment, a detailed rehabilitation plan is made with the patient. Rehabilitation is preferably in their own region but, in case of complex problems and needs, it will be in the unit.

We then visited the Norwegian National Advisory Unit for Rehabilitation which aims to:
- provide knowledge, teaching and advice regarding health services, support equal access to care and the implementation of guidelines
- advise government on requirements for rehabilitation for rheumatic patients.

The value of involving patients

Interesting presentations were delivered on the complexity of sustained access to rehabilitation (eg hydrotherapy), the status of patient involvement in research which is valued but is also a prerequisite for research funding.

Finally, we visited the patient education (learning and coping) centre which offers various educational courses for patients with different RMDs or with different needs. The value of involving patients, also in the development of educational programmes, was stressed.

On day two we visited Norsk Revmatikerforbund (NRF), the Norwegian League Against Rheumatism, where we received presentations by NRF and BURG (the organisation for young rheumatologists) and Birte Glüsing (EULAR) participated in the visit.

"Growing need for specialised HPRs"

As we all know, the demands made on HPRs within rheumatology will increase in years to come. The treatment burden of rheumatic and musculoskeletal diseases (RMDs) is currently growing, while we observe a general lack of rheumatologists. As a result, we will witness a growing need for specialised HPRs. The ESCHPR works continuously on initiatives that focus on the competencies of the HP workforce. EULAR embraces the great variability of countries with very different healthcare systems. We have a great responsibility to continue to further develop the comparability of training received in different countries, to ensure the same quality of care for people with RMDs across all EULAR member states.

The ESCHPR Educational Sub-committee has developed an educational strategy that has recently been ratified by the EULAR Executive Committee. The next important milestone in this work will be a EULAR Task Force, assigned to unveil the core competencies among HPRs within rheumatology. This work will be very important for the ongoing development of HPs around Europe.

Finally, I will take this opportunity to encourage you all to attend the 2017 EULAR Congress in Madrid. I think we have so much to offer in terms of a superb programme, high quality abstracts and the opportunity to network with colleagues from all over the world. So please join us.

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

During the past months, we have been occupied planning the next congress in Madrid: abstract scoring, session planning and awards. Every year sees an increase in both the number and quality of the abstract submissions to the congress. This year is no exception as the EULAR Standing Committee of Health Professionals in Rheumatology (ESCHPR) has received a total of 323 abstracts, which is the highest number ever. I take the increase of submitted abstracts as an expression of a very promising development among HPs around Europe, and I think it is something to be very proud of.

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Time to say goodbye

From Christina H Opava, EULAR Vice President representing Health Professionals

By the end of this year’s congress, I will have passed the Vice President gavel on and left my official service to EULAR after four years. My service began in Madrid in 2013 and, so, the circuit will be closed in the same beautiful city. It is hard to believe that it is already over but, when I think back on all our joint efforts, hard work, great accomplishments and the friendships I have made with wonderful, dedicated European health professionals in rheumatology (HPR), I realise that the amount of time it has taken was probably reasonable.

Of the seven strategic objectives 2012–2017 established by EULAR, EULAR HPRs chose to work with three.

• By 2017, EULAR will have increased the quantity and quality of HP-led research projects and strengthened patient participation.

• By 2017, EULAR will have strengthened education for patients and health professionals by developing tailored materials and improving access.

• By 2017, EULAR will have developed and implemented a communication and PR strategy to address the individual needs of patients, physicians/researchers, health professionals, and corporate members.

“This seemed to be mission impossible”

With Rikke Moe and Michaela Stoffer in the lead, the HPR Scientific Sub-committee has tried to identify the quantity and quality of HP-led research in rheumatology for the first objective. This, however, seemed to be mission impossible since many scientific medical journals do not report the profession of their authors, nor do they share such information on request. Another strategy employed in the search of HP-led research was to identify senior researchers among HPs in rheumatology and search for their publications. However, this strategy failed to demonstrate development over time since many previous senior HP researchers are no longer active and the present ones did not publish as much as research leaders in the past when they were juniors.

“The quantity and the quality of HP-led research has increased”

Nonetheless, I am absolutely convinced that both the quantity and the quality of HP-led research has increased. One major indication of this is the record number of high quality HPR abstracts submitted to this year’s congress. Furthermore, our successful academic mentorship programme, led by Prof. Jo Adams, will assure the growth of the next generation of HP researchers in rheumatology.

When it comes to the education of health professionals, our Educational Sub-committee, led by Prof. Thea Vliet Vlieland, has taken huge steps since it was established in 2013. Thus, an online course, tailored to the needs of HPs, has been launched and is very well attended. It is also now recognised by the Dutch authorities in the accreditation system for HPs and we certainly do hope that they are just the first country among many to follow. We now also have an Educational Strategy for HPs in rheumatology that was approved by the EULAR Executive Committee in March.

The next step will be to identify generic competencies for HPs in rheumatology, which will be done in a project approved by the Executive Committee in March. Last, but not least, the launch of the School of Rheumatology, where HPs have their own dedicated classroom with Thea as “headmistress”, will provide educational materials, based on the needs assessment and competencies identified, and be a major source of development for HPs in rheumatology.

During the past five years, EULAR HPs have also raised our profile, both within and outside the organisation. Our membership has doubled and now includes HPR associations in 25 countries. The HPR Vice President, along with the Vice President representing PARE, now has regular strategic meetings with the EULAR Steering Group, is visible on stage at the General Assembly and also at the opening ceremony of congress.

All our three objectives include patient collaboration and I have certainly enjoyed this collaboration in numerous task forces, such as those for the PARE Annual Congress, the Patient Research Partner project and the World Arthritis Day Task Force.

This is a year of celebration for EULAR, with the HPRs celebrating our 30th anniversary. I wish you all success in your future efforts to continuously improve HPR education, research and clinical practice aiming at better health and functioning for people with rheumatic and musculoskeletal conditions!
It is a nice tradition to ask the incoming EULAR President to present themselves and their plans for the immediate future in the newsletter of the EULAR Health Professional in Rheumatology.

Let me first introduce myself. I was born in 1950 in the city of Heerlen in the south-eastern part of the Netherlands, near the Dutch borders with Germany and Belgium. In 1968, I moved to Utrecht to study medicine and, since then, I have spent most of my time in that charismatic city which was described from the earliest times in Julius Caesar’s De bello Gallico. After finalising my medical training, I married Josette, my wife for over 40 years with whom I had three remarkable children. Following additional training in tropical medicine, we went to work together in Biharamulo, a very rural area of Tanzania. In 1978, we returned to Utrecht, where I completed my specialisation in internal medicine and rheumatology and wrote a PhD thesis on “Hormones and Bones”.

I have worked as a rheumatologist in the department of Rheumatology & Clinical Immunology at the Utrecht University Medical Centre since 1983, serving as its Chair from 1989-2013. Our research addressed rheumatoid arthritis, especially treatment strategies and the use of immunomodulatory therapies, including glucocorticoids. In parallel, I have studied osteoarthritis, particularly focusing on phenotyping the different forms of osteoarthritis that, even now, are so troublesome in society.

I have often worked with Dutch patient organisations and Dutch health professionals, especially during my years as president of the Dutch Society for Rheumatology. Thereafter, together with a psychologist and a nurse, we created the first extended training course for nurses in the field of rheumatology in the Netherlands. Moreover, with the psychologist Rinie Geenen, we coached many PhD projects in this field. Only last December, Judy Ammerlaan, RN, successfully defended her PhD thesis on patient self-management.

I have passed the age at which I’m allowed to see patients in our University Hospital and am thus retired from that position, though I still work one day a week at the University for research and training purposes. Retirement has not brought diminution of my activities. I now commit extensive time to activities for EULAR, and teaching requests from all over the world keep me busy three or four days a week. I use my “spare” time with my wife, travelling, swimming, walking, reading and, of course, taking precious time with our five grandchildren.

Now to your questions…

Your term as EULAR President starts during the organisation’s 70th anniversary year. What do you believe has been EULAR’s biggest achievement since its inception?

In its 70 years, EULAR has developed into a unique organisation, bringing together rheumatologists, scientists, health professionals and patients who have been able to reduce the burden of rheumatic and musculoskeletal diseases (RMDs) on the individual and society. This has been achieved in part by supporting the improvement of the treatment, prevention and rehabilitation of RMDs. As stated in our 2005 EULAR mission statement, EULAR fosters excellence in education and research in the field of rheumatology. It promotes translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the governing bodies in Europe.

EULAR has done so very well at building the necessary critical mass of skills to optimise care – the growth of the health professional organisations to over 20 European countries is a perfect example of this.

What are your priorities for the two years of your Presidency and what do you see as the biggest opportunity for EULAR overall during that time?

My priorities as the next president of EULAR for the coming two years are to:
• further develop the School of Rheumatology
• support the large public awareness campaign: Don’t Delay, Connect Today!
• refresh the EULAR Strategy for the period 2018-2023.

I hope and expect that the pillar of EULAR formed by health professionals will take an active role in the co-operation that is necessary to reach our common goals.

Where do you consider health professionals to have had the biggest impact on EULAR’s work and mission during their pillar’s 30 years of existence?

In 2015, the American health professional organisation asked their past President Teresa Brady to describe progress in the field. Our
EULAR health professionals can be very proud of the important part that Europeans have played in the below-formulated worldwide developments she identified. Three practice paradigm shifts have delivered a big impact on managing patients with RMDs, based mainly on science performed by health professionals.

1. The widely used “self-management programmes” that evolved originally from information giving and “patient education”.

2. The positive and intensive use of “exercise and physical activity” that were developed from the previously-acclaimed bed rest and assisted range of motion exercises only.

3. The OMERACT-initiated definitions and applications of patient reported outcome measures that have complemented and added value to biomedical assessment of disease activity.

In addition, two important “evolutions in practice” have been realised. Namely:

1. understanding psychological factors – from accepting “the arthritic personality” to actively addressing depression, anxiety, coping skills, sense of control and confidence

2. the worldwide development of the important role that nurses and other health professionals can play in the treatment of patients with RMDs.

What are your expectations of Health Professionals in Rheumatology during the next period in EULAR’s development?

There are two answers to this question: one relating to the health professional organisation itself and one relating to EULAR. With regard to the health professional organisation, I think it is important to support an organisation of health professionals in rheumatology in each country that prospers as an active organisation; and to improve education on RMDs for health professionals by e-learning, by international “teach the teacher” courses and national symposia.

I’m quite optimistic that language problems relating to educational materials can be tackled by innovative approaches and means, such as Google Translate, academic health professionals, and co-operative rheumatologists and scientists. Research by health professionals will be stimulated further, not by directly funding research (EULAR has no budget for science; the FOREUM organisation is now responsible for this element of our mission), but by creating modules in the School of Rheumatology and organising small meetings (such as on clinical research, epidemiology).

With regard to EULAR, the best evidence of the integration of all three pillars would be that it becomes very difficult to see what is specifically related to doctors, to patients or to health professionals. Working together with respect for each other ultimately leads to one high quality, universally useful EULAR product.

The HPR network is made up of many sub-specialties and professions. How do you think they can best work together within EULAR to bring optimal care to people living with RMDs?

I’m quite aware of the range of different sub-specialties and professions within the health professional network. I believe that everyone who works for a significant amount of her or his professional time in the field of RMDs is very welcome in our organisation. It is well known that the composition and knowledge content of the different sub-specialties may differ significantly from one country to another, and that some activities may not map similarly from one country to another – for example, in one country a nurse may perform tasks allocated to a psychologist in another.

So, we should be careful not expend energy on discussions about who is allowed to do what. Rather, EULAR should try to produce the right educational materials to help these workers in performing their tasks at an optimal level. Accreditation of these educational products is an ongoing priority for us – I was very pleased to hear that the HP Online Course is now officially accredited by Dutch authorities for health professionals.

How is EULAR adapting to the fast-changing world – one with ever growing financial challenges? What role do you see HPs and patients playing and how would EULAR support them in that?

Changes in finances may indeed become a problem for EULAR in the coming years. The operational costs of EULAR (activities and programmes for patients, health professionals and physicians) are presently well above the income EULAR activities generate – even though our operating costs are efficient when benchmarked with other similar organisations. So, if we don’t want to decrease our activities, such as our recommendations, our educational courses, the Brussels lobbying or the patient activities such as the PARE Annual Conference and World Arthritis Day just to mention a few, then we have to become creative in either reducing costs or increasing income – or perhaps both.

Receiving donations, which is rather common in the United States but not in Europe, might be one such exciting opportunity. It probably starts with an increasing awareness of the size and impact of RMDs on the individual and society as a whole. We especially appreciate the help of health professionals and patients in this area. Don’t Delay, Connect Today!
2017 is the 30th anniversary of the EULAR Health Professionals in Rheumatology (HPR) network. In 1987, five European HP leaders were elected to form the first working group for health professionals. Their aim was to establish health professionals as a partner within EULAR. HPR News has invited the working group members to share their memories, as well as two other individuals who played vital roles in the establishment of the network.

Vicky Stephenson

Vicky Stephenson was involved in EULAR from 1979-1990. She is now retired as a rheumatology specialist nurse and lives in the Lake District in the UK. Here she explains why sharing learning and experiences has been so important.

“My first experience of EULAR was in Wiesbaden, West Germany 1979. There was only a very sketchy programme for HPs, most of which was delivered by medics, although physiotherapists were more catered for.

I got involved in EULAR through being invited to speak at various meetings organised by the EULAR patient organisation Social Leagues (the old name for PARE). These meetings happened in places like Frankfurt, Marbella, Leuven and Enschede. Back then, the meetings were supported financially by pharmaceutical companies and took place under the patronage of EULAR.

In 1984, Dr. Eimar Munthe, the immediate past President of EULAR was especially keen to promote health professionals within EULAR and helped influence the outcome. In addition to EULAR meetings, I also took every opportunity to attend the International League Against Rheumatism (ILAR) to network with HPs internationally.

After Wiesbaden, HP programmes gradually became meaningful and better reflected roles allied to medicine. Moscow in 1983 was a good example of slow but steady improvement. What motivated us HPs to come together was, I think, that HPs had a thirst for knowledge and a desire to learn from each other. I consider some of the early successes must be the way in which HPs could access colleagues nationally and internationally. As part of the first Working Group, it was a relief to be toiling with other like-minded professionals instead of feeling that I was, by and large, working alone.

The biggest challenge in the early days was proving to some medics that HPs in collaboration could only improve patient care. And our biggest achievement was becoming recognised across Europe and in the wider international field.

My message to HPs working in rheumatology today would be to continue to learn from each other and carry on expanding the body of knowledge for the care of patients with RMDs who need holistic care from a well-informed healthcare team.”

Angelika Kruse-Jensen

Originally from Athens in Greece, after studying for her pharmacy degree in Austria, Angelika Kruse-Jensen moved to Norway in 1962. From 1969, she worked at the Diakonhjemmet Hospital in Oslo, latterly as chief pharmacist. Now retired, she shares her memories of key moments in the history of the HPR.

“The Standing Committee of Health Professionals in Rheumatology was formally founded by EULAR in 1989. The committee was the brainchild of Vicky Stephenson, a British nurse, and myself at a 1983 meeting in Marbella. Also included were Ulla Nordenskiöld, an occupational therapist, and social worker Willy Peeters.

Four years later, I presented an abstract at the 1987 EULAR Congress in Athens, Greece, focusing on patient education to enable patients to safely administer their medication. It was during this congress that we arranged the first meeting with other health professionals. Among these was Ingrid Due Pedersen*, a Danish occupational therapist, who was invited to join the new HP Working Group. At this first meeting, we agreed to establish our own group within EULAR called Allied Health Professionals (AHP). Each European nation was invited to nominate one participant to AHP.

From the beginning, we received excellent support from Dr. Eimar Munthe, head physician at Diakonhjemmet Hospital and the EULAR Executive Director, Fred Wyss, who was positive towards the new committee from the outset.

We focused on organising AHP meetings alongside EULAR Congresses – disseminating information and sharing experiences and lessons learnt from various countries. We constantly endeavoured to present the work of AHPs through the publication of scientific articles and participation at professional symposia.

Poly-pharmacy and good adherence to achieve better pharmacotherapy was always my
professional focus – the right administration of medication and the right pharmaceutical drugs to the right patient. This reduces complications and side-effects, and encourages patient compliance with the medication. This is especially relevant for rheumatology patients who are often affected by chronic diseases and use various pharmaceuticals.

Co-operation between professionals from various health sectors involved in rheuma care has proved mutually beneficial for all parties involved – both in terms of building proficiency and in sharing knowledge. Last, but not least, it benefits the patient!"

Willy Peeters

Social worker Willy Peeters, from Belgium, became the 2nd Chair of the new HPR Working Group. Willy passed away in 2009 at the age of 59. This contribution about him has been put together by Danielle Crols (Willy’s widow and retired social worker), Violette Demeester (occupational therapist, retired), Mariette Welkenhuysen (head nurse, retired) and Michel Walravens (rheumatologist, retired) who all worked closely with Willy at the University Hospitals Leuven.

“Willy was a key team member in the rheumatology department at the University Hospital Leuven campus, Pellenberg in Belgium. As a social worker, he strove to ensure the psychological well-being of every patient and, consequently, sought to integrate this element into his local rheumatology team and the work of international health professionals.

Willy had excellent language skills, participated in meetings and gave speeches to various patient organisations. He could co-operate particularly well with all team members. For many years, he volunteered as the secretary of the Ligue for Connective Tissue Diseases, and was a cofounder of ELEF (European Lupus Erythematosus Federation, now Lupus Europe).

A visit to a hospital in the Lake District, UK aroused his commitment to meeting with health professionals from different countries. In collaboration with Prof. J Dequeker and his team of rheumatology, the first symposium for health professionals took place in the University Hospital Pellenberg in 1986.

In 1987, Willy Peeters was elected the 2nd Chair of EULAR’s new AHP Working Group. His experience as a social worker brought a good balance to the team of HP specialists leading this new network.

Between 1987 and 1996, several international symposia were held for health professionals. The 1st, 2nd and 5th Symposia were held in Leuven Belgium, and were all organised by Prof. Dequeker and Willy. The 1st Symposium was attended by 113 HPs from 12 countries. The 2nd Symposia grew to 153 HPs from 14 countries. Topics were as relevant then as they are today! They included technology for disabled people, psychological aspects of care and functional evaluation of the patient.

Willy remained involved in the development of EULAR’s HPR network and delivered a speech at every HP symposium until his career turned in another direction after participating in the EULAR Congress in Nice in 2000.”

Ulla Nordensköld

Ulla Nordensköld was born 1935 in Gothenburg Sweden and now lives in Stockholm. In 1960, she graduated with a diploma in occupational therapy and went on to obtain a teacher exam in OT, and then studied economic science (health and medical care administration), pedagogics, health economy and rehabilitation science, all at the University of Gothenburg. A PhD followed in 1996. Here she remembers her involvement in EULAR:

“For the most part of my career I have been involved in the care and rehabilitation of patients with rheumatic and musculoskeletal diseases (RMDs) in Sahlgrenska University Hospital. My main interests have been patient education, everyday tools and assessment methods. I have developed study material on ‘Joint Protection for Active Living’ which includes a course, slide series, patient booklet and provider manual.

As one of the five founders establishing the first EULAR Health Professional Working Group, I was involved in congress planning, educational initiatives and strategic work for more than 20 years.

One of my interests during my involvement with EULAR was education. From 1998-2002, I actively contributed to the ‘Rheumatology Action for Eastern Europe’ project, developing educational activities in Lithuania, Czech Republic, Poland and Hungary. We developed courses, lasting 2-3 days, which provided patient education and rehabilitation programmes aiming to help patients to learn from each other, to discuss technology in daily activities, and to cope and live with RMDs.

We found that involving patients as active participants in a group patient education setting to be an effective intervention – but it was not a common intervention in all countries. Therefore, we taught HPs about teamwork, group education and the psychological aspects of rehabilitation – always highlighting that the patient had a contribution to make. After these HP courses, we realised that it is important to know the situation of each country before organising a course with regards to the political and healthcare situation.

The work continued with the EULAR Health Professional Strategic Plan for 2002-2005 which aimed to promote high quality, evidence based interventions and to support HPs in the different countries with their multidisciplinary team, including people with RMDs.”
Fred Wyss was Director of EULAR from 1985 to 2007. His backing during the formation of the Health Professionals in Rheumatology was essential in securing its place in the EULAR structure. He shares his memories of the time:

“I strongly supported the effort to launch a EULAR Standing Committee on Health Professionals in Rheumatology. HPs used to be considered a sub section of the Social League of patient organisations (now PARE), which was ridiculous. The Executive Committee did not realise that the Social Leagues were something completely different from the health professionals which, to my mind, were linked more to the scientific part of EULAR. However, that idea was not to the gusto of the mostly medical doctors of the Executive, who felt that HPs should not be on the same level as medical doctors.

After the International Symposium for Health Professionals in Rheumatology held in Leuven, Belgium in September 1986, there were heated discussions at the EULAR Executive Committee on whether a Health Professional Standing Committee should be founded. It was first proposed that the health professional organisations could become corporate member of EULAR – similar to pharmaceutical companies.

It was Vicky Stephenson from the UK who persuaded the EULAR Executive that HPs should have their place within EULAR as a Standing Committee and the decision was ratified by the 1989 EULAR General Assembly.

Unfortunately, it took some time for European health professional associations to decide to apply for EULAR membership. In various countries, there were too many associations involved – for example, nurses, physiotherapists. All had their own local associations and did not want to apply jointly as one society representing their country.

To date, the value of having health professionals as a part of EULAR – and their presence at the Annual EULAR Congress with their own programme – has been enormous, and especially of benefit to patients. To my mind, this is the most important aspect.”

Jana Korandova comes from the Czech Republic. Until December 2015 she worked as chief nurse at the Institute of Rheumatology. Nowadays she is partly retired and works as a quality manager assistant. She tells HPR News about becoming the first Vice President of EULAR, representing Health Professionals:

“I first met EULAR in 1995 at the EULAR Congress in Amsterdam where I represented the patient organisation Rheuma League. At the time, the EULAR Social Leagues (SL) and Health Professionals in Rheumatology worked closely together. However, HPs realised that the level of HP knowledge, practical skills and competences differed across Europe and that our attention should be focused on the education of HPs themselves.

The role of EULAR Vice President, representing Health Professionals was created in 1997 and I was delighted to be appointed to the new position. Along with the Chair of the HP Standing Committee, Nora Price from the UK, my main task was to prepare the HP programme for the annual congress.

We soon realised that we had underestimated two key issues which significantly affected HP participation at our meetings – funding for congress attendance and language skills. HPs being repeatedly unable to attend meetings and having no stable working team became almost intractable barriers for the effectiveness our work. It took quite a few years to be solved. At that time, we had no internet, email or mobile phones either! Despite this, we managed to organise several successful training programmes where a number of HPs had their first experience of ‘how treating people with musculoskeletal disorders could be done in a new way’.

Probably there were more failures than successes during that time, but I believe our first challenges helped set a solid base for all the present successful HP activities. We now have 22 country members and another three to be ratified in June, clear statutes and rules, strategic objectives with concrete goals, projects and research grants, education visits, recommendations for management, study groups.

It took a long time, but now HPs have a functional and well-functioning organisation which builds on all important aspects of EULAR – all of which have formed its past success.”

Members of the 1st EULAR HP Working Group 1987

Vicky Stephenson, UK – nurse
Willy Peeters, Belgium – social worker
Ingrid Due Pedersen, Denmark – OT
Angelika Kruse-Jensen, Norway – pharmacist
Ulla Nordenskiöld, Sweden – OT

*We were unable to reach Ingrid due Pederson for her contribution.
Advocating for prevention and retention

Neil Betteridge, EULAR’s Liaison Officer, Public Affairs reports on activities relating to work and the workplace

In the last piece for this newsletter I reported to the EULAR health professional (HP) community on EULAR’s 2016 World Arthritis Day Conference: “Reducing the burden of chronic diseases in the workplace - new policies for better working conditions and the retention of ill people at work”. So here I would just like to update you with progress on this topic.

As always, the aim is to develop policy recommendations based on members’ wishes – and to use those recommendations as a means of effecting changes in policy in favour of people with rheumatic and musculoskeletal diseases (RMDs), and those who support them.

So, it was an excellent opportunity when, just weeks after the conference, a EULAR delegation met with Ms. Inge Bernaerts, a Member of Cabinet of Marianne Thyssen, Commissioner for Employment, Social Affairs, Skills and Labour Mobility. This delegation included Tanja Stamm representing the HPs and was an opportunity to present our case to the European Commission on the main topics featured in our conference:

i) prevention of RMDs in the workplace
ii) timely access to occupational therapists and other HPs
iii) the retention of people with RMDs in the workplace.

We explored how EULAR might work with the Commission on these issues and Ms. Bernaerts stressed the important contribution that organisations like EULAR could make in the development and implementation of Health and Safety at work (EU OSH) policies in particular. It was clear to us that RMDs are a high priority at EU level in relation to this topic and, in the first part of 2017, the Commission published a new policy piece on work, “Safer and Healthier Work for All”, to which EULAR has responded.

Going forward, EULAR continues to advocate for EU and national policy initiatives on prevention and retention. As part of this campaign, run partly in conjunction with EU-OSHA, the European Agency for Safety and Health at work, EULAR will support member organisations which are active on this issue to advocate at the national level. We are calling for the implementation of existing EU legislation, with the goal of ensuring full compliance of companies of all sizes, as well as pushing for best practices to become widespread.

Meeting in the European Parliament on Rare RMDs

EULAR provides the secretariat for the MEP Interest Group on RMDs, which meets three times a year in the European Parliament. In December 2016, it met to discuss “Policy issues and challenges in the treatment and care of rare diseases”, with a focus on rare RMDs.

There was keen interest in the establishment of European Reference Networks (ERN), specifically ReCONNET, an ERN aiming to improve early diagnosis, patient management and care delivery across the rheumatology network using affiliated centres throughout Europe. Some good news here is that during 2016 ReCONNET was chosen as one of the ERNs to receive support from the European Commission and we will continue to support this network with our public affairs activity.

Update on research and innovation

The other policy priority for EULAR in 2017 is research and innovation, with the key objective being to promote further EU support towards research and innovation in the field of RMDs. Following the ongoing mid-term evaluation of Horizon 2020, EULAR also aims to contribute to the development of the next Research Framework Programme (2021-2027).

One of the ways in which EULAR is promoting this issue is via RheumaMap, our newly-developed Roadmap for Research in RMDs. Prof. Iain McInnes has led the task force from all three EULAR pillars which contributed to this work, which was launched in the European Parliament in May 2016. RheumaMap identifies a number of unmet needs and priorities in research and innovation in RMDs which have been addressed in order to reduce the enormous burden of these conditions.

Furthermore, the 2017 EULAR Congress features a session on Horizon 2020 where RheumaMap will be officially presented. The aim is to discuss the research needs of the whole RMD community, and highlight ways in which the European Commission can support research and innovation in this area.

The role of HPs here is crucial to help shape the next major research agenda: please attend the session on Saturday 17 June, starting at 8.30am.

Finally on this topic, please note that EULAR’s annual World Arthritis Day conference in Brussels will also look at the future of health research and innovation after Horizon 2020. The aim of the conference is to develop recommendations for the new EU Research Framework Programme. This is another important opportunity for the HP perspective to be central to this activity, so do please save the date and join us. It will be held on 17 October 2017 in Brussels.
Reflections on positive collaboration

As EULAR and the Health Professionals in Rheumatology reach key milestones, PARE leaders past and present reflect on how collaboration between patients and HPs leads to greater wins for people with RMDs

HPs and PARE are well connected

By Dieter Wiek, Chair of the EULAR Standing Committee of PARE 2014-2017

For patients with rheumatic and musculoskeletal diseases (RMDs), health professionals (HPs) play a pivotal role in treatment and even in diagnosis. Thus, it is crucial that patient representatives collaborate with HPs and contribute to their work.

Patients who have experienced high-quality treatment by HPs in specialised clinics are often confronted with an outpatient reality in their home environment, where standards of care are not met. Since 2014, I have represented PARE as a member of the HP Educational Sub-committee. The sub-committee has examined the educational needs of health professionals from their European member organisations and, now, the task is to develop, execute and evaluate an educational core curriculum for HPs in rheumatology. Here PARE’s patient organisations – and even informed patients – can support the implementation of these educational opportunities.

In recent years, the co-operation between PARE and HPR in the EULAR Congress programme and the active participation of EULAR HPR in the PARE Annual Conference and the Engagement or Knowledge Transfer Programme has verified how useful it is to include the patient and HP perspective to foster organisational structures or patients’ quality of care.

Patient participation in research

Maarten de Wit, EULAR Vice President, representing PARE 2005-2009

Over the last decade, EULAR has shown a sincere interest in collaborative research. It has facilitated PARE to develop recommendations for patient participation in scientific projects and to establish a network of trained patient research partners (PRPs). The role of PRPs is to act as an equal member on a research team or working group, and to provide patients’ perspectives throughout the course of a project.

PRPs are always involved in the developments of EULAR disease management recommendations. They take responsibility for making sure that important concerns of patients are not neglected and are incorporated in the discussions. But they are also involved in the review of lay summaries of recommendations and other scientific publications to make them understandable for patients.

In some countries, PRPs translate lay summaries in their national language and publish them on the website of the PARE member organisation. The tasks of PRPs are becoming more diverse, varying from assessing grant applications, contributing to third party steering committees and representing EULAR in, for example, the EMA.

A passion to change the world for people with RMDs

By Neil Betteridge, EULAR Vice President, representing PARE 2001-2005 and 2009-2013, International Liaison Officer since 2013

Something which closely unites EULAR’s patient group network is a passion to change the world for people with RMDs. During the 15 years I have been working for and with PARE, the advocacy work has become increasingly effective – to the point where the European institutions, such as the Commission, now explicitly recognise RMDs as a major disease.

The reasons for this impact are manifold. Firstly, the vision of those people at the turn of the century who developed the PARE Manifesto, the first common “agenda for change”. Secondly, the fantastic support of the EULAR Executive Committee and Secretariat when the former Social Leagues became PARE and became truly integral to everything EULAR does. But, above all, the energy and commitment of the PARE members themselves, who just never give up! Working in close collaboration with the EULAR Health Professionals in Rheumatology is an essential component of this success.

“Nothing about us without us” is not just a slogan. It is a fundamental right to self-determination. This is what makes us strong.

Benefitting people with RMDs in Europe

Marios Kouloumas, EULAR Vice President, representing PARE 2013-2017

The participation of patients and HPs in EULAR throughout its 70-year history has been determinative in strengthening research and management objectives, and in raising awareness of the individual and societal impact of these diseases – plus the need to make effective health policies to address these.

It is with great satisfaction that we have seen the growth of HP organisations within EULAR. Our excellent co-operation and interaction has managed to highlight issues important to our participation in all EULAR structures and actions, as well as those of the management of RMDs with non-pharmacological interventions and self-management.

The participation of HP representatives in various PARE working groups and programmes has helped to greatly improve quality and outcomes. We are delighted that, through PARE participation in HP sub-committees, we add and contribute to the development and implementation of the programmes aimed at healthcare professionals. We are confident this co-operation will continue towards the benefit of people with RMDs in Europe.
EULAR HP Winter meeting 2016

The meeting was held 8-9 December in Munich, Germany with 25 participants. Other than the health professional (HP) leadership, participants were members of the HPR Scientific and Educational Sub-committees and a country president representing a national HP rheumatology organisation preparing to apply for EULAR membership. All participated in a common introduction, the launch of the new EULAR HP slide collection and updates on current EULAR work. Workshops were then held separately by the two sub-committees.

Scientific Sub-committee
By Christina H Opava

The Scientific Sub-committee focused on two areas: an overarching strategy for projects on recommendations/points to consider for the practice of health professionals in rheumatology, and idea-generation for innovative congress programme formats and content.

So far, EULAR has applied a bottom-up strategy to projects and encouraged individuals to submit proposals to their respective Standing Committee to take forward to the Executive Committee to either approve, suggest modifications or reject. In the past, some projects have had a very narrow focus, while others have applied a wider perspective to a certain area. The September Executive Committee meeting discussed future project proposals applying a more comprehensive perspective to avoid “salami slicing” and to better inform clinical practice. Consequently, the sub-committee discussion was very timely.

Numerous ideas for projects relating to HP practice were generated. Some examples were HP promotion of work retention/return to work, support of healthy lifestyle and personalised care. We will continue to work on this and integrate the ideas in the recently established EULAR task force with the same aim.

Each year, it is a major challenge to create a congress programme that is adequate and attractive to the HP community, with its large variations in education, practice, professional interests and language skills, within the eight sessions available for the HPs. While some HPs graduated from a few years in polytechnic schools, others hold academic degrees in their respective professions. Some work full time in clinical practise, close to patients with RMDs, and come to congress to learn more about the latest developments in medication, nursing, rehabilitation and psychosocial counselling to take back and integrate in clinical work. Others work entirely within the academy, far from patients and daily clinical practice, and come to learn more about detailed research results and advanced research methodologies.

Thus, our inspiring discussions focused on the identification of speakers and content that could satisfy as many HP needs as possible – one example being high quality qualitative research. We also identified the need for innovative session formats that could still fit into the rather strict congress format. Suggestions included keynote speakers, academic debates and stand-up acts to illustrate a clinical or scientific challenge that could then be discussed with the audience.

They will be fed into general discussions with the EULAR Executive Committee and Programme Committee, and will continue at our next sub-committee meeting in Madrid in June.

Educational Sub-committee
By Thea Vliet Vlieland

During the Winter meeting, the Educational Sub-committee addressed two topics. Firstly, a project proposal*, to be submitted to the spring meeting of the EULAR Executive Committee, to develop EULAR recommendations/points to consider for HP core competencies in rheumatology. Secondly, suggestions for future educational activities to be executed by HP teachers in the School of Rheumatology and additional project members.

The development of a core set of competencies for the management of people with RMDs was considered very relevant as this could form the basis for the development of educational offerings for HPs. During the discussion, several suggestions for the project application were made. These included the definition of the HP target groups, with the outcome being to first focus primarily on nurses, and physical and occupational therapists. Moreover, the importance of involving HPs from different countries was highlighted, as health and educational systems vary largely across Europe. For the latter purpose, it was suggested to involve panels of HPs from various countries via the national presidents of rheumatology HP organisations in the developmental process.

Regarding future educational activities to be executed by the HP teachers in the EULAR School of Rheumatology, several possibilities to enhance the EULAR HP Online Course were proposed, including the addition of video recordings of presentations and language-enhanced summary materials. Accreditation of the EULAR HP Online Course by national professional organisations was very important, just as more extensive promotion of the course among HPs across Europe.

Regarding other educational offerings, the development of a face-to-face course, preferably in a Southern European country, was prioritised. This conclusion was, in part, based on the outcomes of a previous survey among HPs, demonstrating that the need for such a course was found to be the highest in this area of Europe.

* The project application has since been approved.
Gere Luder, PT MSc and Christine Müller, PT MSc from the Department of Physiotherapy, Inselspital, Bern University Hospital, Bern, Switzerland report on their EULAR Clinical Visit in Bristol and London, February 2016

Generalised joint hypermobility and joint hypermobility syndrome (JHS) have been researched at Bern University Hospital (Berne, Switzerland) for many years. Several projects have generated new ideas and more patients have come to the rheumatology clinic in search of help. Through literature reading, we noticed that a research group in Bristol and two clinical physiotherapists in London published regularly in this field. We met them at several congresses, including EULAR 2013 in Madrid and these meetings led us to arrange a visit to Bristol and London, which was supported by a EULAR educational visit grant.

An informative programme

On 16 February 2016, we met with Shea Palmer, Prof. of Musculoskeletal Rehabilitation in the Department of Allied Health Professions at the University of the West of England. For our two days in Bristol, he had organised a programme to meet two PhD students and visit the biomechanics lab on the campus. Shea first talked us through his recent projects: the development of the Bristol Impact on Hypermobility Questionnaire and a therapy intervention pilot study, developed together with patients. Then Sarah Bennett, a psychologist and PhD student of Shea’s, presented her project which aims to look at the psychological impact of JHS.

In the afternoon Naila Siri, a PhD student from Kuwait, showed the results of her PhD project dealing more with biomechanical aspects of JHS. She performed gait analysis, proprioception measurements and looked at muscle properties by ultrasound, comparing persons with JHS and healthy controls. These measurements of tissue stiffness and elasticity by ultrasound are a new approach and we will try to introduce similar measurements in the research projects at our hospital.

The second day started with a visit in Bath, a city near Bristol with a long tradition of spas, local natural warm water springs and a nationally-recognised centre for rheumatological diseases. We talked with Sin-ti Towison, a senior physiotherapist, who regularly treats patients with JHS and was involved in the studies led by Shea and his team. After lunch, back on the University campus in Bristol, Gere presented an overview of our recent research projects in Bern. About 15 students and researchers attended the talk, and a general discussion concerning research projects in the musculoskeletal area followed. Shea recorded the talk on video and it can be seen on YouTube (https://www.youtube.com/watch?v=bYq1JFfecKk).

Experienced therapists

On 18 February, we travelled to London to see the clinical side of JHS in the UK. At the Hospital of St. John and St. Elizabeth in north London, we met Rosemary Keer, one of the lead physiotherapists in the Hypermobility Unit. We observed the treatment of a few patients and two patient examinations by rheumatologist Dr. Alan Hakim. It was interesting to see how important the conversations were between the physio or rheumatologist and their patients. Giving advice to patients, guiding them in their daily life activities and teaching them how to move and exercise without pain were important aspects of the therapy and rheumatology consultation. Another interesting aspect to watch was the fluency and concentration of the treatments. As physiotherapists, it is always very exciting to observe such experienced therapists. Their therapy sessions often have more craftwork, rather than only a treatment.

On the Friday morning, we had the opportunity to observe autonomic laboratory testing. In Bristol, we had heard that patients with JHS often experience postural tachycardia syndrome (PoTS). This is a form of dysautonomia, associated with orthostatic intolerance, excessive tachycardia and several other symptoms. At the hospital in London, patients with JHS are often tested for PoTS.
in the lab. The procedure takes 2-3 hours, testing various movement and exercises and observing the reaction of heart rate and blood pressure. It seems that this kind of dysregulation occurs often in persons with JHS, but exact data is not yet available. Here again, new ideas for research projects and collaborations between our hospitals arose.

Finally, we met Dr. Jane Simmonds, the other lead physiotherapist at the hospital. Jane is an academic at the Institute of Child Health at University College London and combines her physiotherapy research and education work with clinical work, focusing mainly on treating children and adolescents with JHS. Interestingly, we observed the importance of parent education. We saw a very difficult, but also interesting examination, of a 14-year-old patient who had been diagnosed with Ehlers-Danlos syndrome – hypermobility type and autism. She could not verbalise intelligibly and displayed unpredictable movement patterns. But Jane was calm and able to give the young person and her parents helpful advice about how to move rehabilitation forward.

The parents raised a difficult question about how much their daughter really walks and exercises – and how they could increase the amount. A simple idea from Jane was to obtain data from an activity tracking bracelet – this would allow the team to establish a physical activity baseline and then facilitate a graded approach to reconditioning. So, it would be possible to see how much she really moves and to have an idea of how much recovery the girl needs. This was a motivating application of new technology in the therapy setting.

Focus on patient education

Following this educational visit we have had several ideas for implementation in clinical practice: the treatment in physiotherapy has to be individual, in many cases with slower progress in exercise and strength training compared to other persons, because of lower physical capacity. A very important focus in physiotherapy is to facilitate body perception. Fatigue was a new aspect for us in hypermobility, which we should take into consideration during treatment. Management in a multidisciplinary team offers great benefit for the patients. Special explorations for PoTS, gastrointestinal treatment or psychological advice are available, if necessary, which is a new approach compared to Berne. Finally, the focus on patient education is very important and we hope to support this through translation of the booklets and by providing a German language smartphone app.

Overall, it was interesting to see the rather large differences between England’s public health system, called the National Health Service (NHS), and the private sector. There are different ways of patient management in both systems and the amount of physiotherapy delivered in the NHS is usually much smaller than in private hospitals. In Switzerland, we also have both sectors but there are quite small differences between the two – mainly because, in most cases, health insurance (which is mandatory in Switzerland) pays for the private sector.

The second obvious difference for us was to see that interdisciplinary work in a team is much more important and usual than in Switzerland. This was the case in Bristol and Bath, in both research and in the clinic, as well as in London. Both physiotherapy and occupational therapy are involved. Communication between the rheumatologist and other medical doctors is well established and, when necessary, psychologists or social workers can also be involved in the management of a patient. Even the manager of the special school was involved in the therapy session with the 14-year-old girl mentioned above.

A centre of excellence for patients

Over a year has now passed since our clinical visit to the UK and several new aspects have been incorporated into our daily work. Patients with JHS from different areas of Switzerland come to visit the physiotherapy service at the University Hospital and the department is becoming a centre of excellence for these patients. They are treated with manual therapy, exercises to change their posture, strength and endurance training. Even more important is that they are informed about JHS and receive advice for daily life, their work life and for sports and recreational activities.

For patients who understand English, we provide the information material we received from Bristol and London. In the long-term, we want to provide the material in German and we plan to translate and validate the Bristol Impact on Hypermobility Questionnaire for the use in clinics and research projects.

Finally, we intend to carry out a research project with a single case experimental design to investigate the effect of motor control training in patients with JHS.

This clinical visit was an important experience to improve the management of patients with JHS in Switzerland.

EULAR awards up to 10 bursaries for educational visits to 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
Reaching out

EULAR continues to work towards growing its health professional network membership. We hear from two members at different stages of their journeys.

National HP member organisations of EULAR:
Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Denmark, Finland, France, Hungary, Ireland, Israel, Malta, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Spain, Sweden, Switzerland, UK

From June:
Croatia, Germany, Italy

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

hpr Switzerland
By Agnes Kocher (President), Karin Niedermann (Past President), and Urs Gamper (Founding President) on behalf of the board of hpr Switzerland

Following Swiss participation in the annual EULAR Standing Committee meetings of Health Professionals in Rheumatology (HPR), there was a desire to have a similar, intensive inter-professional collaboration in Switzerland. In 2000, the first HPR symposium was realised and the hpr Switzerland interest group was born involving those participants.

The hpr Switzerland association was founded four years later in 2004 and joined the EULAR HPR network in 2006 as one of the first two country members. In order to integrate hospitals and clinics, it was decided to introduce individual and institutional memberships. Today we have about 70 individual members and 15 institution members from the German and the French parts of Switzerland.

Hpr Switzerland aims to facilitate the education of HPs and MDs and support them in delivering best quality care for individuals living with musculoskeletal conditions. We achieve this through:
• inter-disciplinary and inter-professional teamwork
• collaboration with national medical societies and patient organisations
• initiation of research and evidence based practice.

We provide access to information about our projects and activities, the hpr symposium, the biannual newsletter in German and French, and EULAR news on our website (www.hpr-switzerland.ch). Our members can find actual publications, treatment concepts and a member list for networking.

The scientific symposium we hold every second year is one of the main tasks of the hpr board members. We perform an education session with the latest insights into a major topic in rheumatology presented by invited speakers, and have abstract presentations from scientific research and practice development – with prizes going to the two best projects.

Our projects
Implementation of EULAR patient education guidelines: This relates to the implementation of the recently-published patient education (PE) in inflammatory arthritis (IA) patients (Zangi et al, Ann Rheum Dis, 2015) guidelines. The board of hpr Switzerland, in co-operation with rheumatology clinics, the Swiss League Against Rheumatism (SLAR), and the Zurich University of Applies Sciences, evaluated the current standard of PE in Switzerland as well as the agreement with – and application of – the EULAR PE recommendations in order to develop further implementation steps. The manuscript is in preparation.

Definition of core competencies of HPs: In line with the EULAR education strategy, hpr Switzerland aims to define the generic competencies of HPs in rheumatology in our country. Currently, we are developing a short questionnaire for rheumatologists and HPs to capture the perception of HPs’ tasks and educational needs. The results will be the basis for an educational concept to be discussed among the involved HPs and rheumatologists.

Achieving high quality care for individuals living with musculoskeletal conditions is a constant aim of hpr Switzerland. We intend to continue our current strategies of maintaining HPs’ position in rheumatology healthcare by investing in high quality education for our members and making research results available.
British Health Professionals in Rheumatology

By Dr. Jill Firth BHPR President

British Health Professionals in Rheumatology (BHPR) integrated into the British Society for Rheumatology (BSR) in April 2013 and were joined by the British Society for Paediatric and Adolescent Rheumatology (BSPAR) in 2015. The whole organisation exists to unite and support members of the multidisciplinary team in delivering best quality care for our patients. Almost half the BHPR membership comprises nurses working in rheumatology, but there are over 500 members with representation across physiotherapy, occupational therapy, podiatry, pharmacy, psychology and other disciplines.

The first BHPR President, Vicky Stephenson, was also the first Chair of the EULAR Standing Committee of Health Professionals in Rheumatology in 1989. The UK contribution to EULAR leadership has remained strong and Dr. Jackie Hill was our President at the time BHPR formally joined EULAR in 2006. She firmly believed in the power of EULAR as a conduit for dissemination of information and practice, and felt that meeting HPs from other countries could be mutually beneficial. By uniting HPs working in Europe, we have been able to raise the profile and gain recognition for the value the multidisciplinary team adds to patient outcomes and experience.

Opportunities to network and share emerging evidence

In fact, collaborations with EULAR predate official membership, with the jointly-organised first five-day health professional programme at the XIV EULAR Congress in Glasgow attracting a record number of 369 delegates in 1999. Following our membership, a tri-partite collaboration in 2008 meant that the BHPR and Royal College of Nursing undertook a national nurse / HP survey which EULAR then adapted for use within Europe. Whilst there was considerable variation across the 27 participating countries, 92% of health professionals indicated they were performing extended roles and the survey highlighted the need for greater educational opportunities (Stamm and Hill, 2011). EULAR’s Standing Committee of Health Professionals in Rheumatology, study groups and congresses provide important opportunities for BHPR and BHPR members to network and share emerging evidence and resources with other organisations.

In the UK, recent advances include the findings of the first two years of the national clinical audit for rheumatoid arthritis led by the BSR. Higher specialist nurse numbers per head of population were shown to be significantly associated with starting DMARDs within six weeks (odds ratio 1.58; 95% CI 1.00-2.50); and combination DMARDs within three months of referral (2.01; 1.21-3.33). There was variation in access to the multidisciplinary team across England and Wales and provision of specialist podiatry was particularly low and patchy, indicating room for improvement. You can read the report on our website: (http://rheumatology.org.uk/resources/audits/annual_report/default.aspx)

BHPR shares EULAR’s vision to provide high quality educational provision for health professionals and, in 2017, we are launching a series of nine online modules entitled “An Introduction to Inflammatory arthritis for health professionals” and a series of webinars as a member benefit. Regardless of Brexit, it is important to BHPR to continue to collaborate with EULAR to achieve our joint goals to provide educational and knowledge sharing opportunities, and influence health policy to support the delivery of best outcomes for patients.

On behalf of the BHPR, I wish you a happy anniversary and we look forward to future closer working.

References

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 of the EULAR Standing Committee of Health Professionals in Rheumatology, 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 health professional network offers a wealth of opportunities to national health professional associations and their members.

Visit www.eular.org/health_professionals_member_orgs.cfm to view or download your copy of the directory.
Health Professional Study Groups within EULAR

Clinical Nurses’ Study Group

The 2016 session was, therefore, focused on the results of our online survey which revealed people’s future preferences regarding the organisation of the study group. The link to the web-based survey had been sent to nurses in the network and they were asked to send the link to others. 50 nurses responded, of which:

• 16% attended REST
• 14% attended Clinical
• 32% attended both groups
• 34% attended no groups in previous years
• 44% are not sure if any distinction between groups exists.

The most relevant issues agreed were:

1. the convenience of having two linked nurses study group. Attendees said it would be more useful – and more nurses likely to attend – if both meetings (Clinical andREST) were on the same day, over two consecutive hours, but with separate and different agendas.

2. the attendees considered that an annual meeting during EULAR Congress is the best format for SG meetings. Having the opportunity to get in touch with each other during the year was also mentioned.

3. a brainstorm helped identify the clinical problems to prioritise, with six topics being mentioned (see below list). Please contact me (delatorre_jen@gva.es) if you are interested in organising research related to these topics or if you are willing to join other colleagues and share your knowledge and expertise in any of these issues:

   a. ultrasound assessment
   b. transitional care (from youth to adult nurse-led clinics)
   c. nurse prescription regulation
   d. patient adherence
   e. patient involvement in the clinical environment
   f. rheumatology nursing conference.

Since our last meeting, new EULAR SG policies have been approved. From now on, SGs should have a maximum of 25 attendees and an annual poster presentation about the activities and results of the study group by the Study Group Leader must be submitted to EULAR.

I look forward to hearing your feedback and proposal!

Jenny de la Torre-Aboki
Clinical Nurse Study Group Lead

REST Study Group

The REsearch and Strategy (REST) nurses’ Study Group was founded in 2013. We are an international network that includes nurses from Europe and from the Americas, Australia and Asia. To date (end of March 2017):

• we performed 3 research projects resulting in international publications
• there are 2 ongoing research projects with planned publications
• we started 1 educational project (see below)

and we conducted a survey after which we formulated a research agenda comprising 6 topics.

For an update of our activities and results also see the slides at EULAR in Madrid.

The European Specialist Nurse Organisations (ESNO) is a network of European organisations for specialised nurses that aims to improve communication and cooperation between the different organisations and represent their mutual interests within the European Union. ESNO has developed a competency framework for specialised nurses and works on education across boundaries. ESNO representation can benefit EULAR HPs by increasing the visibility of rheumatology HP work and their contribution to multidisciplinary teams on a European level. Nursing can serve as a vanguard profession for other HPs.

Since 2016, EULAR is formally represented within ESNO by Jette Primdahl, Denmark, and myself. The main aims are:

i) to increase awareness and recognition of rheumatology, and the value of nurse-led and HPs care

ii) to serve as a pioneer for a HPs competency framework that fits with the initiatives in the School of Rheumatology.

For more information about ESNO visit www.esno.org

Yvonne van Eijk-Hustings
REST Study Group Lead
The EULAR 2017 Annual Congress of Rheumatology in Madrid will see high quality health professional (HP) scientific sessions which introduce research and issues of interest in HP practice. You will have the opportunity to attend 14 HP 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.

Come and visit our joint EULAR booth in the EULAR Village which, for the first time, will integrate all three EULAR pillars. It is an ideal opportunity to visit the EULAR Health Professional Standing Committee and network with colleagues.

Visit the official website at www.congress.eular.org/ or download the Congress app to your smartphone to access the full congress programme.

### The Health Professional Programme 2017

<table>
<thead>
<tr>
<th>Date</th>
<th>Session title</th>
<th>Session type</th>
<th>Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 June 13.30-14.00</td>
<td>HPR Welcome Session</td>
<td>HPR session</td>
<td>N101/N102</td>
</tr>
<tr>
<td>14 June 15.00-14.00</td>
<td>Wearable technologies in 21st century healthcare</td>
<td>HPR session</td>
<td>N101/N102</td>
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<tr>
<td>14 June 17.00-18.00</td>
<td>Rehabilitation and modern drug treatments: needs and challenges</td>
<td>HPR session</td>
<td>N101/N102</td>
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<tr>
<td>15 June 10.15-11.45</td>
<td>Mind over matter: patients perspective</td>
<td>HPR abstract session</td>
<td>N101/N102</td>
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<tr>
<td>15 June 13.30-15.00</td>
<td>To be and to become: transition from paediatric to adult care</td>
<td>Joint session HPR/PARE</td>
<td>N101/N102</td>
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<tr>
<td>15 June 15.30-17.00</td>
<td>What to do about co-morbidity?</td>
<td>HPR session</td>
<td>N101/N102</td>
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<tr>
<td>16 June 10.15-11.45</td>
<td>Move to improve</td>
<td>HPR abstract session</td>
<td>N101/N102</td>
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<tr>
<td>16 June 13.30-15.00</td>
<td>Fighting osteoporosis frailties</td>
<td>HPR session</td>
<td>N101/N102</td>
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<tr>
<td>16 June 15.30-17.00</td>
<td>Patient engagement in research: benefits and challenges</td>
<td>HPR session</td>
<td>N101/N102</td>
</tr>
<tr>
<td>17 June 08.30-10.00</td>
<td>Trials and tribulations of medication adherence</td>
<td>HPR session</td>
<td>N101/N102</td>
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<tr>
<td>17 June 12.00-13.30</td>
<td>Showcasing the EULAR Online Course for health professionals</td>
<td>EULAR projects in HP</td>
<td>N117/118</td>
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<td>17 June 12.00-13.30</td>
<td>Closing the gap between objective measures and self-report in fibromyalgia</td>
<td>HPR session</td>
<td>N101/N102</td>
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<tr>
<td>17 June 12.00-13.30</td>
<td>Suffering in silence: optimising the management of psychological well-being for people with RMDs</td>
<td>Joint session Pare/HPR</td>
<td>N101/N102</td>
</tr>
<tr>
<td>17 June 13.45-14.45</td>
<td>HPR Highlight Session</td>
<td>Highlight session</td>
<td>N101/N102</td>
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</table>

### Study Group meeting schedule EULAR Congress 2017

There is a capacity for 20-25 participants per meeting

<table>
<thead>
<tr>
<th>Study Group</th>
<th>Date</th>
<th>Time</th>
<th>Room</th>
<th>Study Group Leader</th>
<th>Email</th>
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<tbody>
<tr>
<td>Clinical Nurse</td>
<td>16.06.17</td>
<td>17:00-18:00</td>
<td>A.10.05</td>
<td>Jenny de la Torre</td>
<td><a href="mailto:delatorre_jen@gva.es">delatorre_jen@gva.es</a></td>
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<tr>
<td>Foot &amp; Ankle</td>
<td>16.06.17</td>
<td>18:00-19:00</td>
<td>A10.03</td>
<td>Gabriel Gijon</td>
<td><a href="mailto:gagijon@uma.es">gagijon@uma.es</a></td>
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<tr>
<td>Nurses Research &amp; Strategy</td>
<td>16.06.17</td>
<td>18:00-19:00</td>
<td>A10.08</td>
<td>Yvonne Eijk Hustings</td>
<td><a href="mailto:yvonne.eijk.hustings@mumc.nl">yvonne.eijk.hustings@mumc.nl</a></td>
</tr>
<tr>
<td>Physical Activity &amp; Exercise</td>
<td>16.06.17</td>
<td>17:00-18:00</td>
<td>A10.03</td>
<td>Rikke Moe</td>
<td><a href="mailto:rikmoe@gmail.com">rikmoe@gmail.com</a></td>
</tr>
<tr>
<td>Psychologists</td>
<td>16.06.17</td>
<td>18:00-19:00</td>
<td>A10.05</td>
<td>Eric Taal</td>
<td><a href="mailto:e.taal@utwente.nl">e.taal@utwente.nl</a></td>
</tr>
<tr>
<td>Patient Education</td>
<td>16.06.17</td>
<td>17:00-18:00</td>
<td>S15</td>
<td>Mwidimi Ndosi</td>
<td><a href="mailto:mwidimi.ndosi@uwe.ac.uk">mwidimi.ndosi@uwe.ac.uk</a></td>
</tr>
</tbody>
</table>
EULAR HPR Standing Committee: Meet the national health professional delegates

There are 22 formally ratified EULAR HPR organisations represented by their presidents or other nominated officials at 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 Annette de Thurah and Vice President Christina Opava, discusses ongoing projects and new proposals for the EULAR Executive Committee, initiates the health professional programme for the next Congress, 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.

From June: Croatia, Germany, Italy

Visit for contact details: www.eular.org/health_professionals_member_orgs.cfm

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