Welcome to the winter issue of EULAR HP News. In this issue we have an article by Dr. Mwidimi Ndosi discussing the role of health professionals (HPs) in patient education – given more prominence since the recent establishment of a new study group focusing exactly on this.

Catch up on news about ongoing EULAR HP projects on pain and mentorship.

EULAR’s President Prof. Gerd Burmester shares his plans for his presidency and considers the increasingly important role HPs play in the care of people living with rheumatic and musculoskeletal diseases (RMDs). Additionally, Prof. Anthony Redmond writes his first column as Chair of EULAR HPs – he’s looking forward to opportunities for HPs, especially with regards to education.

Diana Skingle, Past Chair of PARE – EULAR’s patient network – discusses issues raised following the introduction of biologic biosimilar drugs. She shares some of the questions patients have when trying to make informed decisions.

Christina Opava, HP Vice President, is your liaison with PARE. In her column this issue she shares some of the exciting projects and events she has taken part in on behalf of health professionals.

Turn to page 7 for all the details you need about the HP programme at the EULAR Congress in London. Find details about abstract submissions, travel bursaries and even session topics.

Finally don’t forget you can download your copy of EULAR HP News and the members directory from the EULAR website.

Visit http://www.eular.org/health_professionals.cfm

Get in touch

I would love to hear your views on this newsletter – as well as receive contributions and ideas for future issues. 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 HP News
Following on from a very successful mentoring workshop event in Rome 2015, the project team listened to what delegates wanted from a EULAR academic mentorship programme and are now keen to start rolling out the mentorship scheme following the 2016 EULAR Congress in London.

To this end the team is searching for:

a) health professionals who are seeking academic support to understand research and take part in research projects, and
b) health professionals with academic experience to offer support and mentorship to colleagues across Europe.

So, if you are a health professional who is keen to find out more about how to understand research, critically appraise published literature and consider how you could apply research in your own profession and country or you are a more experienced health professional who has previously published, run clinical research and is willing to offer academic mentorship to colleagues across Europe, please get in touch with programme lead Prof. Jo Adams at ja@soton.ac.uk

**HP pain management project kicks off**

A meeting in Amsterdam marked the official start of a project that should lead to health professional recommendations regarding pain management in inflammatory arthritis (IA) and osteoarthritis (OA). Currently, the project is in the systematic literature review phase. The final results of the project will be ready to present to a broad audience in 2016.

The project task force consists of health professionals, patients and rheumatologists from Europe and the United States. It was decided that 1) the target users of the recommendations are healthcare professionals in the field of rheumatology, including rheumatologists; 2) the target population is patients with OA and IA (rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis); and 3) the primary outcome is pain, and secondary outcomes are pain-related emotional distress and functional disability.

Recommendations and the literature review will focus on core prompts for HPs and general pain management that any HP should be able to use, as well as referral to core specialised pain management that is readily available in most (collaborating) institutions.

Research fellow Dr. Cécile Overman is currently conducting the systematic literature review to identify the scientific evidence associated with benefits of the HP approach to pain management. In January, the findings will be discussed during a second meeting of the task force in Amsterdam.

Project lead Prof. Rinie Geenen said: ‘During this meeting, the task force will vote on the recommendations that will enable HPs to provide prompt and knowledgeable pain management support. A professional publication will be prepared as well as a lay version, which will follow the Standard Operating Procedures for writing lay versions of EULAR’s recommendations and for disseminating these recommendations.’

The results will be ready to be presented to a broad audience during the EULAR Congress in London (June 2016) and the ACR/ARHP Congress in Washington (November 2016).

**Mentorship programme moves forward**

**World Arthritis Day 2015 takes social media by storm**

World Arthritis Day 2015 took place on 12 October and EULAR was committed to making it a success. The day generated a lot of support across the rheumatology community, with health professionals, people living with rheumatic and musculoskeletal diseases (RMDs), friends, family, clinicians and decision makers all taking part.

This year, one of the aims was to take social media by storm.

- Over 1,000 High 5 photos were received.
- Over 130 events took place across Europe.
- 222 people, with a social media reach of over 320,000, signed up to “Thunderclap” to enable a synchronised message to be sent at lunchtime on the day itself.
- Social media was exceptionally active with promoted posts gaining 8,939,312 impressions on Facebook and 1,763,745 impressions on Twitter.
- Through carefully chosen Instagram influencers, a 4.78 million campaign reach was gained on Instagram.

See page 17 for information about how Christina Opava, EULAR Vice President representing Health Professionals, supports World Arthritis Day.

Rinie Geenen: Pain Project lead in HP pain management project

Rinie Geenen: Pain Project leader
Learning to juggle

By Anthony Redmond, Chair of the Health Professional Standing Committee

Welcome to my first newsletter as Chair. It has been a lightning six months since taking over in June. I have discovered that the Chair has so many roles to juggle and EULAR is a genuinely fast moving organisation.

I need to start by thanking Sue Oliver for her immense contribution as Chair over the past two years. Sue has been the most dynamic representative for HPs that I can remember in any organisation and, through her enthusiasm, experience, networking ability and relentless thirst for work, she has made a huge contribution to HPs’ role within EULAR. Certainly for me Sue is a very tough act to follow.

This is a very exciting time for EULAR as an organisation. The start of my term as Chair coincides with the Presidency of Prof. Gerd Burmester and you can read about his ambitious plans for EULAR in this newsletter. While EULAR continues to go from strength to strength in a wide range of areas, in the HP section we are focused on three main areas: education, advocacy and research.

Education is at the heart of our efforts. Central to HPs’ position will be the articulation of a clear strategy for HP education in the context of new initiatives. About the time you are reading this, we will be working hard on this at the Winter Meeting of the Health Professional Standing Committee (HPSC) and, in particular, at the HP Education Sub-committee meeting, under the guidance of Thea Vliet Vlieland. I hope to able to share some of the detail of that strategy in the next newsletter.

2015 saw the enrolment of HPs in the first HP-specific version of the EULAR online course. It represents a great resource for HPs as it is likely the existing course will be developed further. Having an agreed core curriculum, supplemented by common assessment of competencies across EULAR countries, will be of great help to HPs. Elsewhere in the newsletter Thea has introduced the work already underway in surveying the educational needs of HPs and this information will be hugely beneficial in informing the shape of things to come.

Don’t forget also that the opportunity exists for HPs to visit other centres to learn first hand from experts and leaders in their field. Josif Meesters has provided us with a wonderful account of his visit to Sweden where he documents not just what he did, but also reflects on how it will influence his practice when translated back to the Netherlands. Finally, on the subject of education – clearly an important theme in this edition of the newsletter – we should not forget the really smart work going on in conjunction with patients and other stakeholders.

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Informing the shape of things to come

Great progress is being made in promoting HP research. After the last HPSC Winter Meeting, we circulated a research strategy and good progress is being made on delivering on it over the coming four years. Look out in future for the excellent work of Michaela Stoffer and Rikke Helen Moe scooping the quality and quantity of HP-based research in the rheumatology literature and also for the outcome of Jo Adams’ initiative around mentorship.

EULAR context.

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Expect to see significant developments

EULAR context.

I hope you enjoy this edition of the EULAR HP News and I look forward to welcoming you to London next June.
Sub-committee round up

Scientific Sub-committee

By Christina Opava, Vice President of EULAR representing Health Professionals (HPs) and chair of the HP Scientific Sub-committee

In 2013, a new scheme was introduced to organise the HP Scientific Sub-committee which will, in the end, result in eight members working together for four years with the HP leadership. The members of the Scientific Sub-committee should preferably have a doctoral degree and represent a wide range of countries and health professions.

To ensure continuity, four members should be replaced by new ones every second year. Following a re-configuration, all eight current Scientific Sub-committee members started their service in 2013 and will continue until 2017. In order to put the continuity scheme in place, we have invited four new Scientific Sub-committee members, Andrea Domján, Annette Sverker, Birgit Prodinger and Norelee Kennedy, to join this year and serve up to 2019. Consequently, for the next two years we will enjoy a larger sub-committee of 12 members, but will be back on track with eight members from 2017. I would like to heartily welcome our new members and I look forward to working with you!

The HP Scientific Sub-committee is constantly striving to reach the Health Professional Standing Committee’s (HPSC) tactical objectives for 2017 about increasing the amount of high-quality HP-led research. Our work on a goal-oriented and academic mentorship programme is one way of promoting not only high-quality research, but also a basis for clinician involvement in research and pathways to faster dissemination and implementation of research results.

Educational Sub-committee

By Thea Vliet Vlieland and Els van den Ende, on behalf of the HP Educational Sub-committee

The HP Educational Sub-committee started a project in October 2014 to evaluate HPs’ future education requirements. The aim of the project is to make an inventory of HPs’ needs regarding education on the management of rheumatic and musculoskeletal diseases (RMDs). The results from the project will be used to constitute a core curriculum for HPs. This goal is in line with one of EULAR’s strategic goals: “By 2017, EULAR will be a pre-eminent provider and facilitator of high-quality educational offerings for physicians, health professionals in rheumatology, and people with rheumatic and musculoskeletal diseases”.

For this project, telephone interviews were conducted with national presidents of rheumatology HP organisations or other national contact persons. Additionally, we surveyed HP clinicians electronically. With this survey, participants could indicate their individual educational needs and preferences, as well as barriers and facilitators to the current and future use of EULAR educational offerings.

By October 2015, 19 telephone interviews had been conducted with representatives from 17 different countries – France, Switzerland, Portugal, Denmark, Hungary, Ireland, Turkey, UK, Czech Republic, Sweden, Austria, Netherlands, Norway, Germany, Belgium, Russia, Spain. Preliminary analysis showed that postgraduate education is more frequently available for nurses than for other disciplines and that joint education of HPs from various professional backgrounds is preferred. For a number of countries, it appeared that the English language is a barrier to taking part in international educational offerings.

The wider electronic survey for individual HPs closed at the end of October 2015. It was ultimately made available in English and nine other languages (French, German, Czech, Spanish, Portuguese, Turkish, Italian, Swedish and Danish). There were over 900 responders, with about three quarters of the respondents using a non-English version of the survey. The number of respondents was >100 for Spain, Italy and France, whereas >50 responses were obtained from Germany, Switzerland, Denmark and The Netherlands. These figures clearly illustrate that HP interest in education is high!

A task force led by Prof. Jo Adams has taken on the challenge to consider and develop a working definition of the role and scope of a EULAR HP mentor, to identify the various possible approaches and components for mentorship to enable a tailored approach for potential mentees, to provide a guide for the qualities and qualifications of a potential EULAR HP mentor, and to discuss how to establish a potential mechanism for identifying mentees (see page 3). A successful workshop was held at the annual congress in Rome, with 43 HPs from 17 countries sharing valuable points to consider for the future work of the task force. This will also be discussed at the HP Winter Meeting in Prague in December.

As a result of last year’s Winter Meeting, the challenge of identifying and quantifying HP research activity published in high-quality scientific journals has been taken on by two Scientific Sub-committee members. We very much look forward to learning more about the outcome.

Another way of identifying HP-led, high-quality research is through major research grants awarded at a European level. We cross our fingers that health professionals will be skilled and brave enough to submit to EUREM and that such an application will be found competitive enough for funding!

Christina.Opava@ki.se
Working together: highlights from the 2015 EULAR Congress

Mathilda Björk, PhD and associate professor, Region Östergötland and Linköping University, Sweden, provides her highlights from the Health Professional programme

This year, EULAR welcomed 14,000 participants to a sunny and warm Rome. Together, the participants represented 120 different countries.

The health professional (HP) programme consisted of 11 sessions, 70 oral abstract presentations, 82 posters and a number of joint sessions with the scientific and patient programmes. The number of submitted and accepted abstracts showed the high quality of research in the HP area. The range of topics discussed was wide: physical activity, ethnicity, evidence-based interventions, innovation, participation, health economics, implementation, fatigue and outcomes.

This year I had been given the honourable opportunity to present the highlights from the HP programme to the HP delegates. Since the programme was extensive, my challenge was to find some “theme” in order to identify the highlights to share.

A recurrent topic during the conference was the importance of the multidisciplinary team working together – along with the patient – to achieve the best possible health and quality of life for our patients living with a rheumatic and musculoskeletal disease (RMD). Hence I chose highlights which covered new research results regarding teamwork, its challenges and possibilities.

Assessment and goal setting are two challenges facing the team and the patient when they first meet. Dr. Mari Klokkerud, from Diakonhjemmet Hospital in Norway, spoke on the topic and presented the national core set they have developed for the assessment and evaluation of rehabilitation in RMDs. They have identified 10 aspects of health and functional assessment and evaluation to measure the effect of rehabilitation. Along with these aspects, they have identified 10 outcome assessments which will be available to use electronically during 2015.

Interventions that can be used by multi-professionals are many. Some I would like to highlight concern team rehabilitation to reduce too much sitting in everyday life. Dr. Bente Appel Esbensen showed that it is possible to reduce sedentary behaviour in people with rheumatoid arthritis (RA) by individually designed SMS (text messages) and motivational interviewing. The reduction of sedentary behaviour led to increased physical function, and reduced pain and fatigue.

Dr. Bente Hamnes, Revmatismesykhuset in Lillehammer, shared participants’ experiences of a group-based rehabilitation programme for returning to work. The participants themselves formulated goals, participated in process-oriented activities and received individual guidance. It resulted in improved experiences of achieving a balance in daily life, new coping strategies, increased quality of life and a healthier lifestyle.

There are many challenges and, especially, opportunities to accomplish multi-professional interventions. Some that were mentioned during the conference included how rehabilitation can be optimised based on multicultural needs, health economic tools to demonstrate the efficacy and benefits of interventions, and the endless possibilities of e-health.

Prof. Ade Adebajo from the UK mentioned both ethnicity and e-health in his presentation where he showed the “Osteomalacia Mindmap” – a tablet-based app used to inform users about osteoporosis in the Urdu language which is widely spoken in Pakistani communities.

The above is a small selection of what was presented at the EULAR 2015 Congress regarding the multi-professional team’s work, development and potential. It shows that HPs’ strength is that we make use of different professions’ perspectives and approaches to enable the best possible health for people with RMDs. The possibilities are endless and much is going on. See you again in London in 2016.

Nina Brodin, PhD, RPT, from Karolinska Institutet and Danderyd Hospital, Stockholm, Sweden, shares the highlights from the HP programme that she presented to PARE

Being given the opportunity to summarise the HP programme really gave me a chance to focus my listening and interaction throughout the Congress. The programme was interesting and inspiring from both research and clinical perspectives – I do not think I have ever spoken to, or interacted with, so many presenters, researchers and patients before at any congress and this was my sixth EULAR!

My overall impression of the HP programme was that we need to work together in order to reach the goals we set. The role of patient involvement in decisions, treatment and development was stated over and over again.

One of the important areas that was summarised this year was ethnicity. In a session asking if ethnicity is a blind spot within rheumatology, we heard about several different types of barriers making it difficult for people from ethnic minorities to access, understand, rely on and communicate rheumatology. And, as stated by a great presenter Mrs. Homaira Khan, reducing
barriers is a two-way job between health professionals and patients. What needs to be acknowledged is that patients are going through pain, inflammation, personal issues, stigma, etc. So what may seem an easy task may, in reality take some time and practice to achieve. Mrs. Khan told us to be patient... And to please keep trying to engage.

In the session on evidence-based practice, Dr. Oonagh Wilson declared that the frequency of foot problems in rheumatoid arthritis (RA), as self-reported by patients, can be used with great confidence. Her study showed high agreement between patients’ self-reports and clinicians’ examination.

In the same session, two studies with novel methodology were presented. Drs. Katie Hacket and Ellen Seltens both presented studies using a method called group concept mapping which captures ideas from stakeholders (eg patients). It allows prioritisation and results in stakeholder-authored maps which identify priority areas, and can guide intervention planning. It is a method I hope to see more of in future studies.

Even in the quite technical health economics session, focus was on the patient perspective and how it needs to be taken into account throughout the entire research process – preferably by including patients from the beginning of a study when choosing outcome measures, so that they will be relevant to patients.

My conclusions from the HP programme this year are that the role of the patient, in all steps of both research and clinical practice, is much more evident than it has been in earlier years. Closer collaboration between HPs and patients will lead to better health.

We now have some work to do before London 2016!

By Anthony Redmond, Chair, EULAR Standing Committee for Health Professionals in Rheumatology.

I really must echo Christina’s comments (right) about the improved quality of the content. A look back over previous years really does show the enormous strides we have made in the quality and significance of the work presented by HPs at the EULAR Congress. This is typified for me in the range of sessions, the sophisticated topics and the quality of individual presentations. We are in the final stages of locking down the content for London 2016 so I know first hand how much planning goes into it – and also how rich are the resources that we can draw on from within our family of EULAR HPs.

Rome was a great experience – now let’s top it again in London.

By Christina Opava, EULAR Vice President representing Health Professionals.

It is great to see the Health Professionals’ congress programme improving exponentially from year to year. It is constantly reaching higher academic standards, while still providing “hands-on” knowledge for clinicians to take back and use to improve the care and rehabilitation for people with RMDs.

A highlight for HPs is always the opening ceremony when three awards are presented to talented health professionals with the best abstracts. Their accomplishments make me so proud and happy for them.

As a personal highlight, I really enjoyed the Health Professional Project Session, attended by health professionals from 17 countries and successfully conducted by Prof. Jo Adams, exploring how academic mentorship could be organised for health professionals in rheumatology. Read more about the session outcome in Musculoskeletal Care.

Submit your abstract now!

Abstracts for EULAR 2016 London can be submitted now – the deadline is 23:59 CET on 31 January 2016. Your contributions are crucial in making the health professional programme relevant and interesting for your fellow delegates. You have until 28 February 2016 to apply for a travel bursary to facilitate your attendance at the EULAR Congress (if your abstract is accepted). This is a separate process and requires a separate application, so make sure to apply as soon as you have submitted your abstract.

A bursary includes:

• free registration
• three nights’ hotel accommodation (single use), booked by EULAR
• a cash amount of €350 for travel and living expenses.

For more information about abstracts visit www.congress.eular.org/abstract_submission.cfm
For more information about travel bursaries visit www.congress.eular.org/travel_bursaries_hp.cfm
Keep up to date via the HP section on the Congress website.

London calling

EULAR Congress 2016 will be held 8-11 June in London, UK. You will have the opportunity to attend 11 HP sessions, including two abstract sessions and two poster tours. Additionally, two joint sessions will be organised with rheumatologists and PARE. Registration for EULAR 2016 London is now open offering early bird prices if you book before 31 January 2016.

Health professional sessions topics 2016

• Different perspectives on pain in osteoarthritis
• Collaboration for success: user-centred design for improvement of health services
• Getting active against rheumatoid arthritis fatigue
• Hand osteoarthritis: state of the art and future perspectives
• Health Professional Welcome Session
• Intimate life and sexual relations in RA
• Physical activity assessment – what do we know, what do we do, how does it work?
• HPR Highlight Session
• Fewer words – more action: tailored care for men with rheumatic diseases?
• Telemedicine and e-health in community/primary care
• Health professionals’ approach to pain management in inflammatory arthritis and osteoarthritis

For more information about abstracts visit www.congress.eular.org/abstract_submission.cfm
For more information about travel bursaries visit www.congress.eular.org/travel_bursaries_hp.cfm
Keep up to date via the HP section on the Congress website.
You have been involved in EULAR for a number of years now. What do you think the EULAR HPs bring to the other two EULAR pillars?

I think the most important achievement for health professionals has been their recognition as an integral yet independent and dependent component in the care for people with rheumatic and musculoskeletal diseases (RMDs). For a long time, many countries regarded HPs just as “helpers” to physicians. Now, nearly everyone realises that without the help of dedicated nurses, physiotherapists, occupational therapists, psychologists and other sub-disciplines, modern comprehensive care is no longer possible.

It is intriguing to see the variety of members in EULAR’s HP network. This ranges from nurses in various positions to psychologists, occupational therapists, nutrition councilors, physical therapists, podiatrists – to just name a few. Thus, they cover a broad spectrum of all the aspects of multidisciplinary team care in rheumatology. All of them have important assignments. This is one of the beauties of EULAR: to learn from experiences, to seek advice and dwell upon the creativity and new approaches to innovative patient care… But also to generate new scientific ideas.

What is your personal experience of working with nurses and with other HPs?

I have been working in the clinical care for patients with RMDs for more than 30 years and have witnessed the tremendous development in this field. Initially, HPs (at least in my country) used to deliver what the doctor asked them to do. Nowadays, they are an integral part of an interdisciplinary team. Nurses, for example, now perform their own special tasks, especially in the outpatient department and the trial unit. These range from history taking, scoring and being masters of the electronic health records, to nurse clinics where nurses (in Germany under the supervision of doctors) are responsible for some areas of patient care. It is quite clear that nurses speak the language of the patients and are, in many respects, better partners to council patients when they are uncertain about how the disease will affect their lives and how to manage aspects of medication.

On a personal note: I worked my way through medical school as a male nurse on night shifts, sometimes caring alone for more than 30 patients. Moreover, I am married to a nurse who worked in an ophthalmology and nephrology department.

The big interview

You have identified education as one of your main priorities. What new opportunities could HPs expect over coming years and how will this support the work of EULAR?

EULAR continues to make tremendous efforts in teaching and education. These range from the EULAR main event, the annual congress, to smaller meetings such as the postgraduate course, and to newer means of education such as the online courses.

We will have various means of providing education such as online courses, physical meetings and information booklets. There may be new material that has not been developed – because it hasn’t even been thought about yet! Perhaps this may change our approaches to education. It is amazing to see the efforts people, including HPs, are putting into these areas, especially since this is all voluntary work.

All in all, EULAR, with the vital help of HPs, PARE members and doctors, can be the world’s primary provider of education in rheumatology. Importantly, education will be provided mostly for free or for only small charge so that the less affluent and developing countries can also afford to participate.

The HP 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?

EULAR has several mechanisms which foster such interdisciplinary co-operation. One is, of course, the HP Standing Committee which is of a somewhat formal nature since, ideally, all countries should be represented here. But as nearly always in EULAR, everybody who wants to join and bring in new ideas is welcome to take part and can ask to be co-opted. Additionally, special focus Study Groups can bring together many sub-specialties. And not least, EULAR will be a forum where all varieties of HPs can interact and learn about new aspects of HP work.

What are your views on how EULAR can help ensure equitable services for patients from country to country?

This is indeed quite a special situation. The levels of training, professional accreditation and scope of practice of HPs can also vary.
widely within EULAR member countries. These methods can differ greatly even within one country – especially if accreditation mechanisms are different from region to region, or not present at all.

In the non-physician HP field, there is no equivalent to UEMS (the European union of medical specialists) which provides universal proposals for postgraduate education for physicians – including rheumatologists – which are frequently followed, at least partly, by individual countries.

What EULAR can do, however, is to set standards through recommendations – such as “What should a specialised physiotherapist in rheumatology know and which competences are necessary”. I believe EULAR will be of great help here by integrating the various requirements for the individual sub-specialties.

**EULAR already does much to support HPs by providing grants for educational visits, free online courses etc. Why is this important to you and to EULAR?**

Health professionals are now an integral part of patient care and research in this area. The help of HPs will be increasingly essential because we already do not have enough rheumatologists in many countries – including my own. HPs will be especially important in early recognition and immediate intensive treatment. An additional excellent example is nurse clinics for patients with well-controlled disease in whom physicians do not have to change treatment anymore, especially rheumatologists. This may be due to the fact that rheumatology was – and unfortunately still is – an under recognised and neglected specialty which does not motivate enough medical students to go into this field. Moreover, in certain countries, rheumatologists leave their country to seek other opportunities in Europe, America and Australia where the working conditions and salaries may be better (or are perceived to be better).

At the same time, acute care which involves higher paid doctors and drug costs is getting more expensive. All of these factors will lead to an inevitable deeper involvement of non-physician health professionals in acute care.

The best quality of care must be our sustained goal. Here EULAR can help to set the standards that are necessary for the essential requirements in patient care as mentioned above.

**Looking at the wider external environment, what do you see as the main challenges for EULAR HPs over coming years, and how could EULAR support them?**

As mentioned, the main challenge is that no central institutions exist which set the standards for education and certification in most areas of HP work. Here, EULAR can come in and establish recommendations for skills and competencies that should be met for best practice.

**How might your other priorities as President influence the work of HPs across Europe?**

There will be three major priorities during my presidency. One is education in which HPs will form an integral part. The next one will be the “Time Is Joint” campaign. Here we have learned from the cardiologists (“Time Is Muscle” – myocardial infarction) and the neurologists (“Time Is Brain” – stroke). Also in RMDs, it is essential to identify and treat diseases as early and intensely as possible to avoid damage. However, it does not suffice to alert the general public and future patients of early signs of their potential disease. We must also offer them early access to care, such as early arthritis clinics.

In view of the paucity of rheumatologists and of a necessary comprehensive and multidisciplinary treatment, HPs will play an essential role here. Even new disciplines might emerge such as the “e-health HP” who can set up new ways of telemedicine and use electronic health record approaches that truly help patients, HPs and doctors alike rather than providing a convenient source for healthcare providers in billing and record keeping.

**What do you see as the biggest opportunity for EULAR overall in the next two years?**

I firmly believe that the particular strength of EULAR – the three pillars: scientists/physicians, people with arthritis and HPs – will lead to the recognition of EULAR as a worldwide eminent provider of the means to achieve the best possible care of people with RMDs. In Europe we have so many excellent institutions, but also have highly motivated individuals who devote their time and best ideas to our field. We can be quite optimistic about achieving new breakthroughs in rheumatology.
Patient education programmes: are the patients in focus?

As EULAR Health Professionals establish a new Study Group for patient education, Dr. Mwidimi Ndosi, School of Healthcare, University of Leeds, UK, discusses the role HPs play in supporting patients

Patient education can be defined as “a planned interactive learning process designed to support and enable people to manage their life with inflammatory arthritis and optimise their health and well-being”. This definition was developed by an international task force comprising interdisciplinary experts and people with arthritis; and though it specifies inflammatory arthritis, it is applicable to many types of rheumatic and musculoskeletal diseases (RMDs).

All patients with RMDs will need some aspect of patient education at a particular time in the course of their disease. This may range from patient teaching and instructions integrated within the context of care, to formal patient education programmes. Since all patients need access to the interdisciplinary team for different aspects of their care, the aim and content of patient education may vary depending on patients’ educational needs.

As well as consulting different members of the interdisciplinary team, each patient is unique and will have different educational needs at different stages in their disease. For example, newly diagnosed patients may need more information, giving individual counselling or patient experience sharing type of activities, while other patients may need self-management education, cognitive behavioral therapies and stress management programmes.

As patients with long-term conditions spend only a fraction of their time with health professionals and undertake most of their disease management activities at home, self-management education has been popular in many countries.

A needs-based approach to patient education ensure that patients’ perceived learning needs are prioritised and incorporated in the educational goals. The overarching learning outcome will remain common: that the patient will be enabled or empowered to self-manage and optimise their health and well-being. This enables the health professional (HP) to think of the learning outcomes from the patients’ perspective, thus making it possible for different HPs to deliver different aspects of patient education, yet aiming at achieving a common learning outcome.

For example, when planning a training session for patients to self-administer injectable medication, the information, the demonstration and the supervised practice sessions will all aim to prepare the patient to undertake this activity safely, but also ensure that the patient feels ready and confident to undertake this task at home. Another learning outcome related to that is that the patient will be able to incorporate this activity in their daily living. Achieving these two outcomes may require inputs from the rheumatologist, the nurse, the pharmacist and the occupational therapist.

The benefits of patient education can be wide-ranging. Some benefits have been well documented in literature, namely from increased knowledge of their disease, coping with disease treatments, self-efficacy and some aspects of health status to mention but a few. Since self-management is related to change of behaviour, the outcome of which can be measured, there is a danger among HPs to limit the benefits of patient education to only measurable behavioural change outcomes. Of course behavioural change is important in people living with long-term conditions, but not all patients need to change their behaviour and different patients will have different ways of coping with the effects of the disease and treatments.

Patient education covers more than behavioural aspects of patients’ lives and indeed the overarching aim of patient education, which is to empower patients, may mean that patients could choose not to have some treatments. Although such a choice may look negative on the surface, it may be a positive outcome if it was a result of shared decision-making. Patient benefits such as locus of control, patient activation and engagement in the management are equally – if not more important – than behavioural change outcomes, as those may determine the quality and the longevity of the behaviour change, if that is desirable.

The process of developing patient education programmes must involve patients for two main reasons. First, people engage more with education if the learning outcomes are relevant to their learning needs. Second, the perspectives of HPs on patient education priorities may be different from patient views of what education is important for them. This means that patients must be actively involved in the process of developing aims and outcomes of patient education. Since the patients have the experience of living the disease, they will have a good idea of what is likely to work for them. Patients’ experience, combined with health professionals evidence based practice, are likely to produce a strong education programme which is effective in meeting patients priority needs.

EULAR has been true to its commitment to providing education to rheumatologists and HPs across Europe via EULAR courses. This year, EULAR has launched the online course for health professionals. Also this year, EULAR recommendations for patient education for people with inflammatory arthritis were published. These are the first recommendations for patient education and they are hoped to raise the standards and enable harmonisation of patient education provisions across Europe. Translation, dissemination and implementation of the recommendations are the first key steps towards achieving this goal.

The recently-formed EULAR Study Group on Patient Education (STOPE) will help to facilitate translation and dissemination of the recommendations. STOPE also aims to promote excellence in patient education research, disseminate research evidence and promote collaboration among professionals and patients interested in patient education across Europe. EULAR will continue to have a central role as a pre-eminent provider and facilitator of high quality educational offering to both patients and health professionals as stated in its 2017 tactical objectives.

References
Reaching out to patients, pharmacists and primary health care — education on launch of prefilled pen injector

By Doris Aquilina, rheumatology practice nurse, and Louise Grech, senior clinical pharmacist, rheumatology, Mater Dei Hospital, Malta

Recently in Malta, a prefilled anti-TNF pen injector was launched on the National Health System (NHS) to replace the previously available prefilled syringe. Most people would agree that patient education on medications is one of the primary target tasks of pharmacists and rheumatology specialists. Without proper education and proper training on how to administer medications, medical conditions — including rheumatic and musculoskeletal diseases (RMDs) — will remain a therapeutic problem leading to noncompliance and a waste of expenses.

Pharmacists and specialist nurses are at the forefront of patient education and very often are the first port of call for patients who encounter problems with medications. On the occasion of the launch of one such pen-based product in Malta, two educational sessions were co-organised by the rheumatology clinical pharmacist and the rheumatology nurse specialist.

One session was aimed at patients on the particular anti-TNF, while the other session was targeted at pharmacists and pharmacy staff dispensing the pen. A third session was organised by the rheumatology nurse specialist targeting nursing staff at the district primary health care clinics. The initiatives were supported by the Clinical Pharmacy Unit and the Nursing Management at Mater Dei Hospital, Ministry for Energy and Health.

The patient education session

The patient education session was held as a morning seminar in order to facilitate patient attendance. The rheumatology clinical pharmacist went through patient information on the anti-TNF drug: what it is, how it works, adverse effects, contraindications, patient compliance and correct storage.

Patients were reminded to seek help from pharmacy staff at their community pharmacies or Mater Dei hospital. Mrs. Doris Aquilina, rheumatology nurse specialist, briefly went through the injection technique for the prefilled pen injector. An educational DVD was used to reinforce patient education on the proper injection technique using the pen. At the end of the session, patients were offered hands-on training using demo packs of the pen, and all patients were given education material on its use.

Seamless care through pharmacy education

In Malta, medications available on the NHS are distributed to patients via the Pharmacy Of Your Choice scheme (POYC). The scheme enables NHS patients to register at a private community pharmacy of their choice, allowing them to pick up their medications from that pharmacy. This system enables the community pharmacist to extend their pharmaceutical care role into medication management related to drugs available on the NHS. It is of utmost importance, therefore, for the community pharmacists to keep abreast of the latest data and evidence-based practice relating to DMARDs and biologic DMARDs.

In the last two years, the rheumatology clinical pharmacist has organised a number of educational sessions to increase awareness, and strengthen the link between the primary care setting and the secondary care settings from a pharmaceutical point of view.

In relation to the launch of the anti-TNF prefilled pen injector, all pharmacists and pharmacy technicians in Malta were invited to attend the educational seminar. The programme consisted of two joint lectures delivered by Ms. Grech, senior clinical pharmacist covering rheumatology, and Ms. Arlette Falzon Seychell, community pharmacist.

Ms. Grech tackled the pharmaceutical care aspects of biologic drugs, including their pharmacotherapeutic role within RMDs. Ms. Falzon Seychell on the other hand dealt with pharmaceutical care aspects of biologic drugs from the practical aspect of a community pharmacist, emphasising advice to be given when dispensing and how pharmacists in the community can monitor rheumatology patients on biologic drugs to maximise patient safety and disease control. The session was ended by Mrs. Doris Aquilina who explained how to use the pen injector, followed by a panel discussion. A summary of the points discussed was compiled and is being distributed through small mail to all community pharmacists in order to reach out those who were unable to attend and as a reminder to those who attended the session.

Educational sessions within Primary Health Care (PHC)

Those patients who do not self-inject attend their respective district health care clinics to receive their treatment. Nurses in the PHC had been given education regarding biologic treatment and, thus, patients could be transferred to their respective health care service. We felt it was very helpful to educate these nurses about the use of the pen injector.

Appointments were made with the nursing officers of each PHC clinic so as not to disrupt the day service. Certain health centres were visited more than once so that we could reach as many nurses as possible. These visits were also used to reinforce education for the nurses about biologic treatment and adverse events. A sample of the pen injector and leaflet were left at each health centre. Patients were also informed that they could go to their respective health centre if they had any problems with the pen. The nurses at the health centres responded very well to these visits.

This national campaign was very important, mostly for the patients as we felt that they needed to be informed about the change in the administration method of their treatment, keeping in mind that the majority of our patients self-inject. The patients were reassured that, once they start receiving the pen injector through the National Health System and if they encounter problems using it, they can seek help through the nurses at PHC, their pharmacists or the rheumatology advice line at Mater Dei Hospital.
The development of biosimilars, and their availability for use in the treatment of rheumatic and musculoskeletal diseases (RMDs), has prompted a vigorous discussion amongst patients and patient organisations in Europe. As the name implies, biosimilars are biologic medicines that are virtually identical in structure to a branded biologic ‘originator’ drug – subtle variations in their ‘make-up’ may occur as a result of their precise design and manufacture.

The European Medicines Agency (EMA) has remarked concerning biosimilars that “when approved… any differences will have been shown not to affect safety or efficacy”. In its paper EULAR Recommendations for the Management of Rheumatoid Arthritis with Synthetic and Biological Disease-modifying Antirheumatic Drugs: 2013 Update, EULAR has commented that “current data suggest that at least one biosimilar, CT-P13, has a similar efficacy and safety profile to the original antibody, infliximab, in RA (rheumatoid arthritis) and axial spondyloarthritis”.

Wider access to biologics
Given the possibility that these new products are likely to be available at a lower price than the originator medicines, new options may arise in terms of wider access to biologic therapies. This in turn could offer a welcome increased choice of treatment, leading in turn to more effective disease management. However, patients have raised a number of questions about biosimilars. Will they carry additional or unexpected risk? Will side effects be the same as the original biologic? Does extrapolation (comparability studies in the context of one disease transferred to other indications) carry additional risk for patients with RMDs? Will cost considerations reduce patient choice?

Patients have also asked, for example, whether the theoretical possibility of switching (transitioning between the original biological medicine and the biosimilar) without patient consent, or interchangeability (going back and forth between the original biological medicine and the biosimilar) without patient knowledge or consent, could introduce unacceptable uncertainties in treatment and outcomes. Moreover, with increasing cross border healthcare initiatives in Europe, will there be differences in national monitoring and approval regimes for biosimilars?

Patients with an RMD accept that all treatments and medicines do carry some risk, as do the diseases themselves. The introduction of new treatments or therapies often brings questions about practical management issues. Patients cannot be fully involved in shared decision-making with their rheumatologist, or make informed choices about their treatment, if they do not have access to – and understand – sufficient information about the medicines that they are being prescribed.

Lay language information on evidence-based data, trials, studies, treatment recommendations, codes of practice etc about biosimilars is therefore vital. Many EULAR national member patient organisations have already raised some of these important issues, and have published national position papers on biosimilars. Drawing on them, PARE recently produced its own paper Biosimilars: What do Patients Need to Consider?

How can health professionals support patients in understanding biosimilars?
Health professionals in rheumatology across Europe can be of great support to patients by providing or signposting relevant, reliable information about biosimilars written in lay language. Nurses in rheumatology are also in a very strong position to offer continuing and trusted support to patients in their eventual decisions, and in their consequent treatment journeys over time.
EU Public Affairs:
tackling difficult topics head on

By Neil Betteridge, Liaison Officer, Public Affairs, EULAR

EULAR holds a public affairs conference in Brussels around the time of World Arthritis Day each October. The overall purpose is, principally, an opportunity to highlight a topic of high relevance to EULAR in a way which also engages senior EU policymakers and other stakeholders involved in the wider health agenda.

These events have helped to position EULAR and its members as an important community in Brussels – to the point where we are now regularly invited by EU institutions to engage in policy development initiatives, thus raising the profile of our disease area and the key issues facing people with rheumatic and musculoskeletal diseases (RMDs), health professionals and clinicians.

The EULAR Public Affairs Group selected the topic of health professionals’ professional mobility, and the importance of patients’ rights when accessing cross border healthcare. All EULAR’s members were consulted in the planning of the event to ensure that we were focusing on the issues which matter, not only at the EU level but to you all.

I am delighted to report that after all the hard work put in by so many people, including our Brussels office and the EULAR secretariat, especially Birte Glüsing, the conference was a huge success.

Position statement
The event was chaired by EULAR President Prof. Gerd Burmester who also launched a new EULAR position statement on last year’s conference topic: barriers to effective healthcare systems. It is important that our conferences are never mere “talking shops”. By concentrating on issues highly relevant to our interests at EULAR, we can use the outcomes from these conferences to provide material which supports our advocacy work throughout the year.

As usual on these occasions, speakers were a mixture of key external stakeholders and EULAR leaders, including the HP Chair Prof. Anthony Redmond whose views on the day you can read on the right. Senior figures from the European Commission spoke, as did MEPs (Members of the European Parliament), on a day which balanced presentations with workshops and panel Questions and Answers to ensure there was plenty of opportunity for audience participation.

In the vanguard
Having been involved in organising these conferences for almost a decade, I have to say that the 2015 event was certainly one of the best. I believe this is partly because the mobility of health professionals across Europe is a huge success.

Anthony Redmond, Chair of the Health Professional Standing Committee, offers his viewpoint on the issues discussed at the conference

This year’s Brussels Conference tackled a thorny issue for health professionals (HPs) in Europe – cross border mobility. While medical and medical specialty qualifications are largely recognised across international borders within the EU, the same is not the case for most HPs. There has been some progress for nurses, but transferability of qualifications for physiotherapists, occupational therapists, podiatrists and others is difficult, if not impossible.

The Cross Border Health Care Directive was the other big issue addressed at the conference. This is an EU directive allowing a citizen of one country to access highly specialised care in another if that care is not available in their own country or if waiting times are deemed excessive. This would be at the expense of the patient’s own country.

The cross border directive will likely have less direct impact on HPs as it relates mainly to highly specialised medical care. Nonetheless, there are potential implications for all HPs – firstly if you work in a unit that has a large influx or outflow of patients or, less directly, if the directive does create significant migration of patients and affects the health systems more broadly. Watch this space.

Although the panel session focused more on the cross border directive and less on cross border mobility of HPs, we had the opportunity to highlight the importance of HPs and point out how far we are behind our medical colleagues in being able to move within the EU. There were some significant examples that give cause for optimism. The European Specialist Nurses Organisation (ESNO), for example, has made substantial progress in this area and there is certainly a model that could be used by other HP professions.

There are difficulties, of course, around the varying definitions and scopes of practice of some HPs across the EU. But we are making progress, as initiatives should introduce some commonality in rheumatology specialty education and certification.
In the Netherlands, osteoarthritis (OA) is a common condition and treatment options are limited – to date no effective disease modifying medical therapy exists for OA. In a recently published treatment strategy for knee osteoarthritis, the BART (Beating osteoARThritis) Strategy, physiotherapy is one of the main non pharmacological approaches for the treatment of knee osteoarthritis. Exercise is also strongly recommended in national and international multidisciplinary guidelines.

Recently, an exercise and education programme for knee osteoarthritis, based on current (inter)national guidelines, was developed and evaluated in the Netherlands: the STABILO protocol. It shows that important symptom reduction and improved mobility occurs after participation in the training programme in knee patients with OA. The STABILO protocol consists of an exercise protocol aimed at improving muscle strength with the focus on knee stability – improving physical condition, performing daily activities, and education about osteoarthritis and how to adequately deal with the impairments.

Figures show that exercise as a treatment for knee osteoarthritis is not optimal in the Netherlands. In 2001, only about 15% of OA patients who were seen by a general practitioner were referred to a physiotherapist. Other research has shown that 36% of patients undergoing joint replacement surgery had never had physical therapy for the affected joint. In addition, the content of physical therapy care of knee osteoarthritis differs significantly between Dutch physiotherapists; and the Dutch Physical Therapy Society's Guideline for Physical Therapy in Patients with Osteoarthritis of the Hip or Knee is insufficiently applied in daily care.

It is important to organise exercise training and physiotherapy treatment for people with OA of the knee in an evidence-based way. Therefore we aim to develop, implement and evaluate an effective, evidence-based practice and education programmes for patients with knee OA. An example of a successfully implemented exercise and education programme exists in Sweden – the BOA project (Better management of patients with OsteoArthritis).

This is a joint project between four geographic regions in Sweden, financed by the national social insurance office and the Swedish government to reduce sick leave and improve rehabilitation. BOA was initiated during 2008 due to the high cost of sick leave caused by osteoarthritis. It was based on the knowledge that only a minority of patients receiving surgery due to osteoarthritis saw a physiotherapist at any time before surgery. Nevertheless, information, exercise and weight control are core osteoarthritis treatments according to national and international guidelines.

The aims of BOA are to offer every patient with OA adequate information and exercise according to the evidence-based recommendations, and ensure that surgical interventions should only be considered if non-surgical treatments have been tried and failed. The goal is to reduce the need for healthcare and sick leave due to osteoarthritis, as well as to increase the quality of life and level of independence and physical activity among patients with osteoarthritis in hip or knee. Patients with OA should receive equal and optimal management on their first contact with healthcare, independent of where this first contact is initiated.

The BOA project involves the perspective of people with experience of osteoarthritis and has established close collaboration with the Swedish Rheumatism Association through the Osteoarthritis Communicator project.

**Aim**
The aim of my visit was, therefore, to gain insight into the management of patients with knee and/or hip OA in Sweden – with the focus on the role of health professionals (HPs).

**Method**
I visited three centres in Sweden on three separate days:
1) Registercentrum Västra Götaland
2) Trollhättan Närhoppl晧Rehabilitation Artroskoja
3) Capio Movement, Halmstad

**Results and discussion**

*Centre 1 Registercentrum Västra Götaland*

From Carina Thorstensson I learned a lot about setting up a structured exercise and education protocol for OA patients, including successful nationwide implementation.

From an implementation point of view, it is very important to provide ready-to-use programmes. However, centres want to have the freedom to tailor programmes to local situations where needed. Also, patients get the opportunity to tailor the treatment to their own needs. Education is, nevertheless, a prerequisite for every patient.

The programme aims to help patients to learn self-management skills to cope with their osteoarthritis largely by themselves. This is an important aim in the Netherlands, and
in Sweden it is a central theme throughout the sessions.

The involvement of a dietician in dealing with issues around weight management is an interesting element of the Swedish programme – a complete one-hour education session is available covering food, weight management and OA. I think we should really consider incorporating this in the Dutch sessions.

Another strong point in Sweden is the direct involvement of patients in the education session. In the Netherlands, we involve patients in the project team, but it would be good to include a patient in the sessions who can stress the importance of movement and exercise to their fellow patients. Patients need role models who experience the same problems, difficulties and challenges as themselves, alongside an enthusiastic physical therapist who explains why OA patients should start exercising.

Of course it is important to collect data to provide evidence for the education and exercise protocol. In Sweden data is provided by physical therapists in the local centres. From the central register, patients receive questionnaires for follow-up. In the Netherlands we have experience providing feedback to the physical therapists by returning aggregated data to them. In the Swedish project, data is also shared between participating centres so they can compare outcomes. This helps motivate centres to keep up their good work – or even improve their work.

Swedish colleagues wish they had more time and resources to analyse the data, and this is also a big concern in the Netherlands. We aim, therefore, to apply for funding to guarantee we can include data collection, management and analysis throughout the project.

Centre 2 Trollhättan Närhälsan Rehabilitation Artrosskola

In Trollhättan I spent a day with Åsa and Johann. I thank them very much for their hospitality. I was able to attend two training sessions, one education session and some individual sessions. It was good to see that they are very enthusiastic about the programme – and the same goes for all the patients.

My colleagues are positive about the programme – it gives a lot of structure to the treatment of patients and also leaves room for the physical therapist’s own input. The patients were very positive because there are many opportunities for training throughout the day. Although they are rather self-supportive in their exercise, there is good supervision by the PTs.

The education session is largely the same throughout Sweden. The session I attended was well received by the patients and by me – although it was in Swedish I could follow the headlines and the context. The timing of the education is very important, and it is always planned to take place before starting the exercise session. Different aspects are introduced; what is OA, what is the importance of exercise, what are the risks of exercise, how to deal with problems after exercise, how to cope in daily life etc.

The PTs say they do not see the task of collecting data as being too much work. They really see the benefits and are always interested in how they perform compared to other centres.

Altogether, I gained a really good insight in the execution of the programme. Keywords that really stuck with me were structure, enthusiasm and self-supportiveness.

Centre 3 Capio Movement, Halmstad

On my way back to the airport I had the opportunity to spend time with my colleague Karina Malm, who is a PhD student and physical therapist in Halmstad, with the Capio Movement. Formerly she used to work at the Spenshult Hospital in Sweden. We saw patients together and had valuable discussions about the multidisciplinary treatment of patients with rheumatic and musculoskeletal diseases. Along the way I learned a new method for testing aerobic capacity that I have taken back to my colleagues in Leiden: the Ekblom-Bak bicycle test, as a substitute for the Astrand test which some patients find difficult.

Additionally, I followed one of the patients, who spoke English very well, during her appointment with an occupational therapist. It was good to see that the way patients are treated in both Sweden and the Netherlands is of a similarly high level.

Conclusions

It was a very inspiring visit that taught me a lot about structured care for patients with OA and about the implementation. Our project in the Netherlands will surely benefit from a lot of the things I discussed and saw in Sweden.

I really hope that, in the future, we will be able to welcome our Swedish colleagues to the Netherlands so that they can see how we work.

Acknowledgements

I would really like to thank EULAR’s Health Professionals in Rheumatology for giving me the opportunity to visit my Swedish colleagues. Also I would like to thank Åsa, Johann, Karina and Carina for their warm welcome, all the arrangements and all the educational moments – we had many inspiring discussions throughout my visit. And last but not least, I would like to thank all the patients I met for sharing their experiences.

Carina Thorstnesson shared her learning from Sweden’s Better management of patients with OsteoArthritis project.

How can I apply for an educational visit grant?

Information about how to apply can be found on the EULAR website at www.eular.org. Applications should be submitted by email to the EULAR Secretariat at gabriela.kluge@eular.org
Making progress

The EULAR Health Professional (HP) Study Groups (SG) met face to face at the annual EULAR Congress in Rome. Here, some of the groups report back on developments.

Foot and Ankle Study Group

The EULAR Foot & Ankle (F&A) Study Group has been very proactive over the last year, and has progressed on many levels. We are pleased that membership has increased to 30, with members now representing 11 European countries. The SG has agreed on a three-phase programme of work looking at the “Identification of the discrepancies in RMDs foot and ankle health service provision in Europe”.

The group has been working on the first phase of the programme of work – a Foot Care Provision survey to identify the current status of foot and ankle health care provision in Europe. This has led to the development and piloting of a rheumatic and musculoskeletal disease (RMD) Foot & Ankle Healthcare Service Provision survey, which is currently being used to undertake the HP country presidents’ survey. The focus of the F&A group for next year is to complete phase one of the programme of work, disseminate the results from the survey and develop phase two of the programme of work (individual practitioner survey).

Dr. Begonya Alcacer-Pitarch, Foot & Ankle Study Group Lead
b.alcacer–pitarch@leeds.ac.uk

Occupational Therapy Study Group

We currently have 32 academic, research and clinical rheumatology occupational therapists (OTs) from 12 countries including Austria, Canada, Czech Republic, Canada, Denmark, Ireland, the Netherlands, Norway, Switzerland, Sweden, Turkey and the United Kingdom. This year, 15 members from seven countries were able to attend our SG’s annual meeting in June. We discussed the role of OTs in the European-wide academic mentorship for HPs with Prof. Jo Adams, Professional Lead for OT at Southampton University, UK and part of a EULAR task force to explore the feasibility of developing this programme across Europe. Our SG members are keen to get involved and support this programme.

We also discussed our progress with the two EULAR HP grants we acquired through collaboration within the SG, and shared updates on the new projects we have started in our own respective countries and the PhD studentships on offer to European OTs. We find our annual meeting is an invaluable opportunity to find out what is going on around neighbour countries in the name of OT. For example, it was news to us that there is a Masters in Occupational Therapy course delivered online in Sweden, which is completely free for EU OTs (see www.universityadmissions.se).

Another topic on our agenda was the use of educational visits to support the collaborative work undertaken within the SG. So far we have secured funding for three educational visits within the SG, which has led to joint grant applications for multi-national studies and comparative data analyses, resulting in funding and published conference abstracts. The group discussed the possibility of conducting secondary analysis on existing datasets to acquire multi-national comparisons on commonly collected outcomes, such as limitation in activities of daily living, social participation, pain, fatigue and effectiveness of tailored hand exercises in people with rheumatoid arthritis.

As we only have an hour to discuss these issues – and each year we manage to barely touch base before the time is up – we deliberated approaching the EULAR committee with a request for an increased time slot. We continue our discussions through emails and other online platforms as fits the purpose. You can follow our updates on Twitter through @EularOT.

Yeliz Prior, Occupational Therapy Study Group Lead
y.prior@salford.ac.uk

Box 1 Study Groups and leaders

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<th>Leader of the study group</th>
<th>E-mail address</th>
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<tr>
<td>Foot &amp; Ankle Study Group</td>
<td>Begonya Alcacer-Pitarch</td>
<td>b.alcacer–<a href="mailto:pitarch@leeds.ac.uk">pitarch@leeds.ac.uk</a></td>
</tr>
<tr>
<td>Nurses Study Group – Clinical</td>
<td>Jenny de la Torre</td>
<td><a href="mailto:delatorre_jen@gva.es">delatorre_jen@gva.es</a></td>
</tr>
<tr>
<td>Nurses Study Group – Research &amp; Strategy</td>
<td>Yvonne Eijk Van Hutchings</td>
<td><a href="mailto:yvonne.eijk.hustings@mumc.nl">yvonne.eijk.hustings@mumc.nl</a></td>
</tr>
<tr>
<td>Occupational Therapist Study Group</td>
<td>Yeliz Prior</td>
<td><a href="mailto:y.prior@salford.ac.uk">y.prior@salford.ac.uk</a></td>
</tr>
<tr>
<td>Physio Study Group</td>
<td>Rikke Moe</td>
<td><a href="mailto:rikmoe@gmail.com">rikmoe@gmail.com</a></td>
</tr>
<tr>
<td>Psychology Study Group</td>
<td>Eric Taal</td>
<td><a href="mailto:E.Taal@utwente.nl">E.Taal@utwente.nl</a></td>
</tr>
<tr>
<td>Patient Education Study Group (STOPE)</td>
<td>Mwdimi Ndosi</td>
<td><a href="mailto:m.e.ndosi@leeds.ac.uk">m.e.ndosi@leeds.ac.uk</a></td>
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Physio Study Group

Our meeting in Rome closed just before the last bus left for the Congress dinner. Thanks to enthusiastic and flexible physical therapists, our meeting was efficient and to the point.

The Physio (PT) SG is growing fast – it consists of approximately 380 members from many different countries. The SG emphasises the importance of physical therapy research within the field of RMDs. It has become a resource for project development, a network for discussing common projects and interests and an umbrella for smaller working groups. For most members though it is an information network. We want to share knowledge, detect knowledge gaps, help each other in applying for educational visits to enable us to cooperate more, and discuss new research calls and possibilities for collaboration. We have also performed a survey to investigate working conditions, physical therapy methods and educational needs of PTs within EULAR.

Getting ready for Rome, we were working to increase the focus on “Intensity of exercise and physical activity in RMDs” and had a very good session at the conference. Next year we will be working on a session about how to measure physical activity.

At the SG meeting last year in Paris, the main theme was how to measure physical activity. Various members have different projects including questionnaires and devices. Collaboration around this focus resulted in a winner of the EULAR HP Research Grant 2015. Nina Brodin presented the project “Physical activity and aerobic capacity assessment – a survey among patients and health professionals in Sweden, Ireland, Denmark and Belgium”. Several representatives announced their interest in an SG working solely with this theme, as a multidisciplinary resource group. Some of us are working on the application right now.

Rikke Helene Moe, Physio Study Group Lead
rikmoe@gmail.com

Yeliz Prior

Dr. Begonya Alcacer-Pitarch

Rikke Helene Moe

Rikke Moe
Nurses Study Group – Research and Strategy (REST)

During our meeting, reports from the Cardiovascular Study Group (CVR) and the Rheumatology Nurse sensitive Outcome Taskforce (RNOT) were discussed.

CVR, an international group of nurses from five countries, performed a systematic literature review, described examples from nurse-led cardiovascular risk assessment and management in the different countries, and formulated a research agenda. The article has been accepted for publication in *Musculoskeletal Care*.

RNOT, an inter-continental group of European, US and Asian nurses, conducted a systematic literature review on nursing interventions and outcome measures in rheumatoid arthritis (RA). Results will be published by the end of 2015, and qualitative data collection will follow that will help in defining outcomes to be measured when studying effectiveness of nurse-led care.

The groups used technical support such as Skype and email for communication, Dropbox for sharing documents, and met, if possible, during EULAR, ACR and/or OMERACT meetings to discuss the status of our activities. We faced several barriers: deadlines did not hold (due to time constraints for all SG members), no funding, many other projects in “the air”, technical problems etc.

Time for discussion was limited as people had to run for the bus to the city centre or to their hotel. An example from nurse-led cardiovascular care was that people had to run for the bus to the meeting was suggested. The nurses from five countries, performed a systematic literature review, described examples from nurse-led cardiovascular risk assessment and management in the different countries, and formulated a research agenda. The article has been accepted for publication in *Musculoskeletal Care*.

The annual PARE Conference 2015 was held in Ireland, with 150 delegates from 33 countries attending. The overall theme for the conference was “Patient-centred Care. Taking Control”. Ireland’s Minister for Health welcomed the delegates and raised a number of important issues, particularly emphasising the role of self-management among people with chronic diseases.

Eight interactive and well-organised workshops were held. Some topics were e-health, self-management, shared decision-making and lay versions of EULAR recommendations. Plenary sessions and selected workshops were streamed and viewed 130 times online and over 500 times via YouTube over the next month. A Twitter wall gained over 1,250 tweets with an estimated potential audience of over 150,000. The 2016 conference will be held in Sofia, Bulgaria on 15-17 April. Do plan to watch streamed sessions and workshops.

Representing health professionals (HPs) within EULAR entails numerous tasks and responsibilities, some really challenging and others just enjoyable — albeit often demanding. One of the many enjoyable tasks I have is to be the HP liaison with People with Arthritis and Rheumatism in Europe (PARE). Below I would like to share some thoughts and learning from PARE activities I regularly join.

The Annual PARE Conference 2015 was held in Ireland, with 150 delegates from 33 countries attending. The overall theme for the conference was “Patient-centred Care. Taking Control”. Ireland’s Minister for Health welcomed the delegates and raised a number of important issues, particularly emphasising the role of self-management among people with chronic diseases.

Eight interactive and well-organised workshops were held. Some topics were e-health, self-management, shared decision-making and lay versions of EULAR recommendations. Plenary sessions and selected workshops were streamed and viewed 130 times online and over 500 times via YouTube over the next month. A Twitter wall gained over 1,250 tweets with an estimated potential audience of over 150,000. The 2016 conference will be held in Sofia, Bulgaria on 15-17 April. Do plan to watch streamed sessions and workshops.

World Arthritis Day (WAD) is celebrated on 12 October each year. The PARE WAD task force does a great job preparing themes and campaigns. Examples of themes during my years on its task force are “Move to Improve” and campaigns such as “Waving” and “High 5” for World Arthritis Day have attracted lots of postings on social media, resulting in the empowerment of people with rheumatic and musculoskeletal diseases (RMDs) and raised awareness in society on their needs. The WAD theme for 2016 will be “The Future in your Hands”. Visit the website to read more and learn how, you as an HP, can contribute!

In October I enjoyed meeting the network of Patient Research Partners (PRPs), helping to facilitate their exchange of experience and, hopefully, increasing their knowledge on how to find relevant scientific literature. Twenty-nine PRPs from different countries have been educated by EULAR PARE in recognition of the central role patients play in task forces, development of recommendations and research projects. Some PARE member countries run their own programmes that are available for collaboration with HP researchers. Read more about recommendations for the inclusion of patient representatives in *Ann Rheum Dis* 2011;70:722-726.

Health professionals are trained to think that we are here to help and assist our patients. More seldom we think about what they can teach us. EULAR HPs certainly have so much to learn from PARE. My examples above illustrate their professional work with awareness campaigns, involvement in guidelines, cutting edge use of social media and empowerment of their members. Let’s learn from them and expand our collaboration to even better serve our memberships!
Reaching out

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

Visit the EULAR Health Professional website to find out how your country could apply for membership.
The Swiss organisation for health professionals in rheumatology has grown from strength to strength since its creation over 10 years ago

By Karin Niedermann, president of the Swiss national society

The national organisation Health Professionals in Switzerland (hpr) was founded in 2004 as one of the first three national health professional (HP) organisations within EULAR. Thus, we celebrated our 10th birthday in 2014, with keynote speeches from our guests of honour Sue Oliver, then Chair of the EULAR HPs, and Walter Kaiser, president of the Swiss Rheumatology Society.

Currently we have about 70 individual members and 15 institution members. The members, as well the board, are multidisciplinary. Members are predominantly nurses, occupational therapists (OTs) and physiotherapists (PTs), but also psychologists and social workers. The board currently consists of two PTs, two nurses and one OT.

During the first years, the main task was building up the organisation – to make it well known and to network with national bodies, especially the national Rheumatology Society and rheumatology patient organisations. The annually-held HP symposium was an ideal platform for these objectives. The symposium has always been part of the national rheumatology congress and is thus visible, providing occasion for direct contact and relevant education to health professionals. Many topics have attracted interested rheumatologists. There, we also award two abstracts for the best HP research and HP practice project respectively.

Increasingly, the hpr board members found they were mainly busy organising our annual symposium. That is why, in 2010, the hpr board decided to hold the symposium bi-annually, giving more time to the (few but enthusiastic) board members for developing the organisation and conducting projects.

A major step was building and developing a website that has been running for five years now and is regularly updated, and new material for gaining new members. We produce two newsletters per year with the two sections “hpr-news” and “EULAR news” to keep our members updated about the activities of our organisation and of EULAR / EULAR HPs.

Besides information, in the “hp section” we promote collaboration and co-activities between the board and members; in the “EULAR section” we promote participation in the Congress, the EULAR grants and bursaries and, most recently, the EULAR HP online course.

Recently, we started a project related to the implementation of the newly-published guidelines for patient education in rheumatoid arthritis patients (Jangi et al, Ann Rheum Dis, 2015), in co-operation with rheumatology clinics and the Zurich University of Applied Sciences.

This brings us closer to a future aim: to become an organisation that is not only distributing available information and knowledge, but increasingly supporting the development of our own – and participating in collaborative – projects. This may also open up opportunities to collaborate more closely and more successfully with the rheumatologists’ society.

EULAR is very relevant for our hpr organisation – as a window to new developments and issues, as source of knowledge and as a great opportunity to collaborate and link with other HPs and institutions internationally for clinical or scientific exchange. Personal contacts with the HPs active within EULAR are very helpful for this. It’s a pleasure to be aware that we have so many great colleagues around!

EULAR has welcomed France as a member of its Health Professionals in Rheumatology network

By Françoise Alliot-Launois, president of Pro Rhumato, the French organisation of health professionals in rheumatology

Pro Rhumato is a non profit organisation for health professionals working in rheumatology in France, dedicated to the development and co-ordination of action to fight against all rheumatic and musculoskeletal diseases (RMDs). It was created in December 2014 for non-medical health professionals who work in care, prevention, accompaniment, research, survey, learning and training.

Pro Rhumato takes action especially with regard to the medical and social consequences of RMDs. This includes the:

- quality of health professional practices in these areas
- support of health professionals from initial training through to advance practice
- development of health education and information for the public
- national and international representation, and the recognition of health professionals’ expertise in national health actions in Europe.

Consequently, Pro Rhumato actively participates in national events and congresses on rheumatology, RMDs devoted to paramedical issues, and scientific and technical or medical-social events in connection with the subject of our organisation, such as Rencontres Nationales sur les Rhumatismes (National Meetings on Rheumatism) and the Health Therapeutic Education Day of the French Society of Rheumatology Section.

In 2015, our main activity has been to develop a strategy to become well known and retain new members. Pro Rhumato is the only HP organisation in France in the RMD field. Having pride in this new challenge, we decided to apply to become a member of the EULAR Health Professionals and our application was voted on and accepted in June 2015. Our board of members was founded formally in Paris on 4 June 2015 and we became a new EULAR HP member during the last Congress in Rome.

Our future challenges are the recruitment of new members, the development of our website and marketing support, and the dissemination of learning and information from Pro Rhumato to our members.
Meet the EULAR HP Standing Committee’s national HP delegates

There are 22 formally ratified EULAR HP organisations represented by their presidents or other nominated officials at the EULAR Standing Committee of Health Professionals in Rheumatology. These HP delegates contribute to shaping health professional activities within EULAR. The Committee, headed by Anthony Redmond 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 HP 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.