Integration is the key to EULAR's success

Maurizio Cutolo is a Professor of Rheumatology and Internal Medicine, and the Director of the Rheumatology Research Laboratory and Clinical Unit at the University of Genoa.

 Having served EULAR for almost 15 years in different positions, including as Chairman of the Committee for Education and Training, and now as President-elect, Maurizio's major clinical investments have been the study of the circadian rhythms in rheumatoid arthritis and a new timing of administration for glucocorticoids in such disease, the contribution of videocapillaroscopy for the early diagnosis of systemic sclerosis and the important role of vitamin D deficiency as a risk factor in autoimmune diseases. Maurizio is supporting the role of neuroendocrine immunology (role of stress, sex hormones, sleep, etc) as a delicate network in controlling people's health and diseases.

Maurizio will start his term of office as EULAR President at the end of the EULAR Congress in Madrid on Saturday 15 June 2013.

EULAR has recently developed a new strategy for the future. What would you specifically like to see accomplished during your term of office?

Maurizio: The finalised EULAR Strategy 2017 consists of seven overall strategic objectives and 20 more concrete tactical objectives. In December 2012, the "stakeholder groups" (mostly Standing Committees) selected three objectives which they want to specially promote and advance in the coming years. EULAR has decided to revise some major objectives which were planned 11 years ago (2002) and they should continue to position the European Society as world leader in education and support for doctors and patients involved in the field of rheumatic and musculoskeletal diseases (RMDs). In particular, Objective 6 declares: "By 2017, EULAR will have raised its profile and visibility to patients and health care providers".

How have you seen the role of patients changing in the past 10 years and what do you expect it to be in the future?

Maurizio: The involvement of the patients' associations inside EULAR has increased in a terrific manner in the last 10 years. Today, we can say that there is full integration and cooperation between representatives of PARE associations and all the other components of the Society. The dissemination and analysis of patient reported outcomes (PRO) and the effects of new treatments, has permitted the optimisation and development of target therapies. However, doctors need to counsel their patients more precisely about the impact of patient lifestyle – including diet composition, correct physical exercise and adequate compliance with doctor prescriptions.

How do you plan to further foster the relationship between the three pillars within EULAR?

Maurizio: Wide and continuous integration.

You have represented EULAR in some national activities organised by the Standing Committee of PARE. What is the benefit for the national organisations to have a wide representation of EULAR key stakeholders present? What does EULAR gain from this type of activities?

Maurizio: Recently, I have been involved in several activities in favour of PARE associations in countries, such as Italy, the Former Yugoslav Republic of Macedonia and Serbia, that asked for the presence of EULAR representatives at local official meetings with their regulatory authorities. I noticed that the authorities highly respected EULAR suggestions and, on the other hand, I collected important information for our internal management and planning.

The economic crisis hits hard in almost all EULAR member countries and many people with RMDs are severely affected. What is your message to the national governments?

Maurizio: The health status is one of the major inheritances of people from which arise the prosperity of the nation and its civilization is valued. Governments are making widespread funding cuts during this economic crisis, but I believe they must continue to pay regard to the care and protection of people living with diseases like RMDs.
This is my last editorial as Chair of the Standing Committee of PARE. However, I believe that real work is not related to titles or positions but to will and personality, so I would like to assure you that I will keep on working for the benefit of people with RMDs in my position as past Chair.

During my term of office, some very important steps have been taken regarding the future vision and aims of the PARE community. Several important activities have been initiated like the CEO Meeting, the e-Breakthrough newsletter and a more active role for EULAR in supporting national organisations. New ideas around the Autumn Conference will be applied this year to improve the quality of the event and ensure the implementation of the outcomes at national level.

A more effective use of existing resources and a more strategic approach has been considered, and the evaluation of current activities has been high on the PARE agenda. We have seen more active participation of people with RMDs in research and the request for their expertise is rising.

World Arthritis Day has become more visible through the successful waving campaign and a big network of supporters has been built through social media supporting awareness raising activities about RMDs. Hopefully this will continue with this year’s activities.

All the achievements above are the result of teamwork supported by our devoted Secretariat, and I would like to take the opportunity to thank all of those who contributed with selflessness and honesty. Last but not least I would like to wish my successor, David Magnusson, all the best for his period in office. My time as Chair was an enriching experience which has taught me a lot of things for which I am grateful.

Maria Batziou is the Chair of the Standing Committee of PARE

DEAR COLLEAGUES

by Maria Batziou

Introducing the incoming Chair of the Standing Committee of PARE

David Magnusson was born in 1953 and has three daughters aged 40, 30, and 29. He is also the proud grandfather of two lovely little girls. David works as a manager for the local non-profit organisations in the region of Jämtland, located in the middle of Sweden. He has had rheumatoid arthritis (RA) since 1984.

Talking about this, David said: “I asked my doctor what I could expect from this disease and he answered that if he had a crystal ball he would tell me. That was when I started to become active, because I realised that much of my future was in my own hands.”

He added: “I became a member of the Swedish Rheumatism Association in 1991 because I realised that it was through this organisation that I could find other people with the same problem that I had. For me, this was when I began to take control of my disease and learnt how to live a good life despite my RA.” David is now the Vice President of the Swedish Rheumatism Association and the Treasurer of his local branch. He has participated in EULAR Congresses since the year 2000 and has made numerous presentations at several of them. He has been a member of the EULAR PARE Board since 2005.

Among several other obligations, David is a member of the Swedish Dental and Pharmaceutical Benefits Agency as a patient representative, and a Board member of the Swedish Disability Federation.

As Chair, David’s focus for the coming years is to ensure PARE’s input and support for the successful implementation of the seven EULAR strategic objectives. One of his personal priorities will be to make the voice of people with RMDs heard more clearly at the EU level in Brussels and to work on strengthening the national organisations of people with RMDs through training and support.

David also would like to further strengthen the involvement of people with RMDs in all EULAR activities, and to get EULAR better known among policy-makers and the public in general.
EMEUNET: high quality, young generation contributors in all EULAR activities

By Caroline Ospelt, Leader of the EMEUNET Visibility Subgroup

In 2009, EULAR leaders approached three young rheumatologists, Maya Buch, Laure Gossec and Daniel Aletaha, and asked them if they could organise the implementation of one of their objectives for 2012: “to bring on board high quality, young generation contributors in all EULAR activities”. They took on the task and set out to build up EMEUNET – the EMerging EULAR Network.

Today EMEUNET is up and running with an ever-growing membership, currently encompassing around 500 members, who can choose to participate at different levels. As community members, young rheumatologists benefit from meeting colleagues from all over Europe and receive regular information about meetings, bursaries etc via the EMEUNET newsletters and webpage. They also have the chance to participate in social events and courses organised by EMEUNET.

To make sure that information from EMEUNET reaches members, every participating country has a Country Liaison, who is in contact with the young rheumatologists and researchers in the country. Apart from disseminating information, the Country Liaisons represent EMEUNET at national meetings and give valuable feedback to the EMEUNET working group. This working group is the organisational core of the network and comprises 35 people, who have to participate in at least one of the six working subgroups dealing with various aspects of EMEUNET activities, including education, country liaison, visibility, webpage, newsletter and peer mentoring.

The Education Subgroup works together with the EULAR Standing Committee of Education (ESCET) and devises sessions for EULAR meetings that are specifically interesting for fellows in training. Also, EULAR courses, awards and bursaries were revised by the Education Subgroup, so that they better fit the needs of young rheumatologists. The Country Liaison Subgroup attends to Country Liaisons by compiling information that has to be sent out, keeping e-mail lists updated and providing material that Country Liaisons might need to promote EMEUNET at their national meetings.

The promotion of EMEUNET on an international level is one of the tasks of the Visibility Subgroup. At EULAR meetings, an EMEUNET booth is set up where members and non-members can meet, discuss and get information about the structure of EMEUNET, its activities, and sessions not to be missed. Exclusively for EMEUNET members, a sight-seeing tour is organised at the city of the meeting by local members.

The presence of EMEUNET on the internet is cared for by the Website Subgroup. The EMEUNET webpage first went online in June 2012 and since then provides members with information about bursaries, courses, upcoming meetings and much more (visit http://emeunet.eular.org). In addition to the webpage, EMEUNET members get new information with EMEUNET newsletters. In particular, the ‘do not miss’ newsletters before, and ‘highlights’ newsletter after EULAR and ACR meetings, are highly appreciated.

The newest subgroup within EMEUNET is the Peer Mentoring Subgroup. Based on two EMEUNET surveys revealing that there is great need for mentoring opportunities among young rheumatologists, this subgroup facilitates the search for a mentor by establishing a list of potential mentors and by initiating meetings between mentors and mentees. Together with the editor of the Annals of the Rheumatic Diseases, the Peer Mentoring Subgroup organised an initiative, in which young rheumatologists had the opportunity to critically review manuscripts that have been sent to the journal together with a senior reviewer, who shared his/her experience in finding the strengths and weaknesses of a research paper.

All the subgroups are kept together by the steering committee, consisting of the current Chair, Peter Mandl, Chair-elect, Pedro Machado, and Past Chair, Laure Gossec. The mission of EMEUNET is to “enhance the quality of research and education among emerging rheumatologists and researchers”.

“Even though EMEUNET is just coming of age, it is already on the right track to fulfil its mission,” said Chair Peter Mandl.
**EULAR family ties on all levels**

By Mikko Väisänen, EULAR HP News Editorial Assistant

PARE members and health professionals work closely together

Together we make a difference. The EULAR family includes 45 scientific societies, 36 national associations of PARE and 11 health professionals (HP) associations. The number of HP societies has been expanding steadily in the past years. EULAR’s aim is for each country to be represented by their national PARE organisation, rheumatology society and health professional organisation.

“This is to ensure that the holistic view of care for an individual is encompassed within the EULAR family, with all of us striving to enhance the individual’s experience of care and improve outcomes for all rheumatic conditions,” said Sue Oliver, Chair Elect of the EULAR Standing Committee of Healthcare Professionals.

The HP Committee works to ensure that expertise and collaboration within the interdisciplinary team will focus on the patient’s expertise and knowledge about their condition. This will enable the individual’s specific needs to be recognised and considered as a key component in delivering high-quality care. It should also capitalise on the full resources of the team whilst ensuring that the individual’s health and wider personal perspectives and needs are taken into account, tailoring the treatment plan accordingly. A specialised rheumatology team could include physicians, nurses, occupational therapists, physiotherapists, psychologists, social workers, nutritionists, podiatrists and other HPs.

The vision above might be easier to deliver in some countries than others, because healthcare provision varies from country to country. Indeed the care that can be delivered, the composition of the health team, working methods, as well as cultural and social structures and, most importantly, the funding of care all add to this complex mix.

That is why EULAR offers such an important contribution by working with our members to identify and then develop guidelines and recommendations that can be of value to HPs throughout Europe. It is hoped, in time, that the whole of Europe will have the essential tools to deliver effective patient-centred care supported by guidelines and recommendations.

### Close links at national level

National HP associations participated in a member survey which reported the importance of close co-operation with local organisations of people with rheumatic and musculoskeletal diseases (RMDs). In many cases the local patient organisation has played an essential role in the birth of an HP society, as we have recently seen in the cases of Cyprus and Finland. For instance, said Oliver: “PARE’s former Chair Marios Kouloumas is the godfather in terms of having facilitated the pathway for the recently founded HP society in Cyprus.”

### Is your country the next?

During EULAR congresses many PARE delegates have visited the HP stand to hear more about the procedure of involving their local HPs with EULAR.

For the moment there are EULAR health professional member associations in Italy, UK, Bulgaria, Czech Republic, Denmark, Switzerland the Netherlands, Norway, Serbia, Sweden and Romania. The HP Committee welcomes newcomers Spain, Ireland, Finland, Austria and Cyprus who are subject to final ratification of their membership at the next EULAR General Assembly in Madrid.

If you do not see your home country on this list, please pass the word to your local health professionals. If your HPs would like further advice about the process of working towards membership, we would be delighted to offer support.

All interdisciplinary HP organisations specialised in the care and treatment of RMDs in European countries are welcome to join in. Please get acquainted with the 5-step plan on how to establish a national HP society and join EULAR.
Asking the questions

Neil Betteridge is the first person from PARE to be appointed to an open position on the EULAR Executive Committee. As Liaison Officer, EU Affairs, Neil will be supported by Prof Gyula Poór from Hungary in the role of Medical Advisor, EU Affairs. Here they talk to Breakthrough about their new positions.

Please introduce yourselves

Neil: For the last four years I have been EULAR Vice President, representing PARE, and have led for PARE on EU Affairs for 10 years. In the UK I was Chair of the PARE member ARMA, and CEO of Arthritis Care. The UK government has twice appointed me to advisory positions working with ministers and my background is as a public affairs specialist.

Gyula: Following my medical graduation in Budapest I took special exams and earned scientific degrees of PhD and DSc. In the 90s I conducted research at the Mayo Clinic and was invited to join the World Osteoporosis Programme of the WHO as secretary of the project. Currently I work as the director general of the National Institute of Rheumatology, and I am a full professor of rheumatology at Semmelweis University.

This is the first time someone whose background is that of a patient representative has led on EU Affairs for EULAR, working alongside a lead clinician. How do you see this teamwork operating in practice?

Neil: Policymakers aren’t usually clinicians, but generalists who prefer issues explained in “lay” language. My professional background has trained me in this sort of political communication. Working alongside Gyula to provide clinical expertise when needed is, therefore, an ideal mix – just as Josef Smolen and I combined well together for so many years.

Gyula: The EU Affairs Group has done tremendous work in the last years. The leader and the engine of this group was Prof Josef Smolen who has been an outstanding personality of the international rheumatology community. Neil gained special experience working alongside him that can guarantee success in the future. My job is pretty tough to replace Josef as a clinician but I will try to support Neil with my clinical output.

The main decisions around Horizon 2020 have now been taken. Can anything be done by EULAR now to further improve the funding for research into RMDs?

Gyula: Unfortunately the acceptance of RMDs is still low among decision-makers, including the EU politicians – although in recent years we have started to see more comprehension and support. Due to EULAR’s efforts raising awareness on the burden of RMDs, decision-makers are starting to pay attention to the need to invest more in these diseases. Although the discussion on Horizon 2020 has not yet finished, the amendments proposed by the EU Council and the European Parliament aim to give more visibility to – or even prioritise research in – RMDs. Now we have to urge our member organisations to submit a large number of projects in order to get the greatest benefit from Horizon 2020.

“By 2017, EULAR will have a significant influence on EU level, and assist actions on national level, towards improving research funding, social policy legislation, and quality of care.” What will your priorities be around Objective 4 of the recently-launched EULAR Strategy?

Neil: To promote strong EULAR networks of clinicians, health professionals and PARE representatives whose combined strength will raise increased research funds; to embed the needs of people with RMDs in the powerful EU disability movement; and to make a difference at country level by promoting best practice in public health, transport and employment policy. Together, this will meet EULAR’s main objective which is to improve the quality of life for people with RMDs.

What can member organisations do to help EULAR fulfil this strategic objective?

Neil: Scientific, health professional and PARE members are the lifeblood of EULAR and the more they can support EU Affairs initiatives, the more successful we will be and the more their own members will benefit at national level. We will be in regular contact to invite such participation.

Gyula: EULAR has always worked for the rheumatology community and patients. This committed activity can only be realised via national member organisations. They transfer the special local needs and they mediate the central intentions to be carried out. Therefore, the relation of EULAR and its members can be demonstrated as that of body and extremities – one cannot exist without the other.
During recent months, EULAR has been very active in Brussels. Among others, EU affairs activities focused on two main areas: public support for research and innovation in rheumatic and musculoskeletal diseases (RMDs); and EU and Member States’ initiatives on chronic disease prevention, particularly the prevention of RMDs.

As part of these activities, EULAR organised three important events.

1) The conference “Preventing chronic diseases for a healthier Europe: The case for rheumatic and musculoskeletal diseases”.

2) The workshop “Tackling the burden of rheumatic and musculoskeletal diseases through research: Towards a European roadmap for research and innovation in musculoskeletal health for the next decade”.

3) The 10th meeting of the European Parliament Interest Group on RMDs, which focused on the EU support to research.

The first two events took place last October, and were co-organised with EFORT (the European Federation of National Associations of Orthopaedics and Traumatology), with whom EULAR founded the European Musculoskeletal Health Alliance in summer 2012.

The Conference aimed to discuss the implementation of chronic disease prevention strategies at both the EU and national levels, paying special attention to the prevention of RMDs.

Presentations and discussions addressed a variety of issues. For example, the individual, social and economic burden of chronic conditions; the EU and national efforts in preventing these disorders (particularly RMDs); the need to focus not only on primary but also on secondary and tertiary prevention; the role of patients in the design and implementation of prevention strategies; and the strategic role of research and innovation in the prevention of chronic diseases.

High-level representatives of the European Commission, the European Parliament, the Cyprus EU Presidency and Member States, together with representatives of the RMD community, were among the main speakers.

Roadmap

In turn, the aim of the workshop was to prepare the ground for the development of a European roadmap for research and innovation (R+I) in RMDs. Such a roadmap is expected to help address some of the main challenges affecting R+I, such as insufficient consensus regarding research priorities; lack of coordination of national research efforts; insufficient collaboration between scientists, health professionals and the industry; or lack of sufficient investment in R+I in RMDs.

The workshop saw the participation of prominent scientists and researchers, health professionals, and representatives of patient organisations, as well as Members of the European Parliament, and representatives of Member States and the European Commission.

One of the main results of the event was the adoption of a preliminary action plan for the development of the roadmap, which will start being implemented in the coming months.

In its role as secretariat to the European Parliament Interest Group on RMDs, EULAR organised the meeting “The EU post-2014 budget and the future of health research: Redefining priorities, improving effectiveness”. The aim of the encounter was to discuss EU support to R+I in the context of financial constraints.

Legitimate concerns

The recently proposed reduction of the EU budget 2014-2020 by the EU Council has raised legitimate concerns about the willingness and capacity of the EU to effectively support R+I – particularly health research. With this in mind, the meeting intended to understand the position of different decision makers and explore possible scenarios for EU health research.

High-level representatives of the key EU institutions presented at the meeting: Members of the Parliament, the EU Council, and the European Commission (both the Directorate General for Budget and the Directorate General for Research and Innovation were represented). Prof Maurizio Cuto, EULAR President-elect, presented the EULAR position focusing on the types of chronic disease research the EU would need in the future.

For more information on these and other EULAR EU affairs activities, please contact the EULAR Brussels Office: Brussels@eular.eu
Bienvenido a Madrid

Spain hosts EULAR Congress 12-15 June

For the first time ever, the capital of Spain welcomes the annual European Congress of Rheumatology from 12-15 June 2013 in the Feria de Madrid. The charming city of Madrid expects to receive more than 13,000 participants to this unique arena for exchanging scientific and clinical information.

In his online welcome address for participants, current EULAR President Maxime Dougados said: “The integration of health professionals and patient organisations within EULAR has proved to be a considerable stimulus for advances in the field. This integration will facilitate the implementation of recommendations for management/standards of care of musculoskeletal disorders in daily practice.”

To endorse the President’s words, Neil Betteridge, EULAR Vice President representing PARE, and his team have prepared a programme specifically focusing on the point of view of people with rheumatic and musculoskeletal diseases (RMDs). “This programme will be diversified in its content, covering topics reaching from intimate daily life issues relating to people with RMDs and their families, and political activity issues such as the use of modern media for campaigning, and also focusing on providing information on latest advances made in degenerative conditions and in biological treatment,” said Neil.

Maria Batziou, Chair of the Standing Committee of PARE, added: “We are delighted that, this year, the number of abstract submissions increased by 50% and we would like to thank all submitters and organisations very warmly.”

For an overall session timetable, please see the overview below, which includes the Joint Sessions organised with the Health Professionals in Rheumatology and the Scientific branch of EULAR. Joint Sessions always provide a useful platform for health professionals, people with RMDs, researchers and clinicians to discuss shared interests and find ways to work more closely together.

To get started, we recommend that you attend the Pre-conference Outlook session, on Wednesday 13.30-14.30, which will provide you with all the logistical details you will need to know your way around the congress venue, as well as provide participants with information about the programme.

As in previous years the PARE Booth will be waiting for your visit and is meant to be the central meeting point for PARE delegates to receive the latest information on PARE activities and to meet their European colleagues to exchange the latest news. Come and visit and get your own copy of the 2013 EULAR Stene Prize booklet as well as many other recent publications.

The PARE Booth will be staffed by two experienced team members, Emmi Myöhänen from Finland and Dragan Chichikj from FYROM, who are both excited and looking forward to their time at the booth. Just next to the PARE Booth, the PARE Posters will be displayed from Thursday to Saturday – use the lunch breaks to talk to the poster presenters in person and get an overview about the manifold activities of PARE organisations.

If, at the end of the Congress, you have not been able to cover all that you had wished to, you can always attend the PARE Highlight Session. Here you will have an overview of the learnings taken from the Congress and its outcomes from the perspective of health professionals and rheumatologists, as well as the first feedback from PARE delegates.

### The PARE Programme

<table>
<thead>
<tr>
<th>Day / time</th>
<th>Session title</th>
<th>Session type</th>
<th>Room Number</th>
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<tbody>
<tr>
<td>12 June 15.00 – 16.30</td>
<td>• Political campaigning: How to influence policy makers at national and EU level</td>
<td>PARE Session</td>
<td>Room N116</td>
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<tr>
<td>12 June 17.00 – 18.30</td>
<td>• Healthy ageing – making a friend of time: How to stay in control of your life as you grow up or grow older with a RMD</td>
<td>Joint Session</td>
<td>Room N116</td>
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<tr>
<td>13 June 10.15 – 11.45</td>
<td>• Rebranding RMDs: What is so special about RMDs?</td>
<td>PARE Session</td>
<td>Room N116</td>
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<tr>
<td>13 June 13.30 – 15.00</td>
<td>• Patients rights to cross border healthcare and other entitlements</td>
<td>PARE Session</td>
<td>Room N116</td>
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<tr>
<td>13 June 15.30 – 17.00</td>
<td>• Gender differences in care and treatment</td>
<td>PARE Session</td>
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<tr>
<td>13 June 15.30 – 17.00</td>
<td>• The concept of health in rheumatic disease: The ability to adapt and self-manage</td>
<td>Joint Session</td>
<td>Room N116</td>
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<tr>
<td>14 June 10.00 – 11.45</td>
<td>• From abstract to concrete – the variety of activities of PARE organisations</td>
<td>PARE Abstract Session</td>
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<tr>
<td>14 June 13.30 – 15.00</td>
<td>• Family planning, pregnancy and parenthood</td>
<td>Joint Session</td>
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<tr>
<td>14 June 15.30 – 17.00</td>
<td>• What’s new? Latest advances in treatment and management</td>
<td>PARE Session</td>
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<tr>
<td>15 June 08.30 – 10.00</td>
<td>• Social media in RMDs</td>
<td>Joint Session</td>
<td>Room N116</td>
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<tr>
<td>15 June 12.00 – 13.30</td>
<td>• The three musketeers – equity for all: Availability, affordability and acceptability of arthritis health care in Europe</td>
<td>PARE Session</td>
<td>Room N116</td>
</tr>
<tr>
<td>15 June 13.45 – 14.45</td>
<td>• PARE Highlight Session</td>
<td>PARE Session</td>
<td>Room N116</td>
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Danish Stene Prize winner’s secret to healthy ageing

“Thanks to my wonderful doctors and to my own personal ‘health recipe’, I now feel better and stronger than I have in a long time – even if, objectively speaking, more is wrong with me now than ever before,” said Mette Toft, 56, Stene Prize winner 2013, from Denmark.

Married to a Japanese university professor and mother to two classical musicians, Mette was one of 19 national finalists put forward from all over Europe by their national organisation under the topic “Growing up or growing older – my secret for healthy ageing with a rheumatic or musculoskeletal disease.” As a member of the Danish Rheumatism Association, Gigtforeningen, Mette heard about the contest from their website. This year’s theme resonated with her, so she decided to submit her essay and give it a try.

Mette has an MA in Japanese and Danish, and taught Japanese at universities as well as Danish as a second language at language schools for adults. She is also an author and has published a few books – an ABC picture book with riddles for children in 1999, and two books on Danish pronunciation for students and teachers in 2002. In 2005 she was diagnosed with systemic lupus erythematosus and other rheumatic diseases as well as multiple contact allergies and multiple chemical sensitivity (MCS).

Jana Korandova, member of the 2013 Edgar Stene Prize Jury from the Czech Republic, representing the EULAR Health Professionals, commented: “This year’s topic was so current, so cool and so inspiring! When writing their story about ageing with an RMD, none of the authors has done so without switching on an imaginary screen – like a life film show. I am sure the screen was multi-coloured, but also full of surprises and new knowledge about themselves. Thank you very much to all those who have shared their film of memories with us.”

The Edgar Stene Prize will be awarded to Mette at the opening plenary session of the European Congress of Rheumatology in Madrid, Spain, on 12 June 2013.

The Network of Patient Research Partners – benefits for all

EULAR has been encouraging researchers to involve patients in their projects for a couple of years. People living with a rheumatic condition every day have different ways of looking at the relevance and conduct of research. Their input gives the outcomes a new dimension.

So far, 15 patients have been trained to participate in research projects and they are constantly involved in several tasks or are active as reviewers of scientific grant applications. In June 2012, the patient research group met in Berlin, prior to the EULAR annual conference. The goal of this meeting was to evaluate the benefits and experiences of the patient research partners during past activities.

All participants confirmed it had been useful and important to be part of task forces, although not all experiences were totally positive. Some participants had come across misunderstandings or had not felt comfortable in working groups. Several suggestions on how the collaboration between patients and researchers could be improved were gathered then, such as better preparation, the use of understandable language or having two patients on the same team.

After the training, investigators were asked to share their experiences of working with patients. All were enthusiastic about the collaboration with patients although they too reported the need for more guidance and easy-to-use tips and tricks to improve partnerships. It was clear that the professionals did not always know what could be expected of the patient research partners.

Using all the input, a set of reference cards was developed, together with a brochure. These materials can be used by both patients and researchers, and contain suggestions to make the best out of the collaboration in the different stages of the research process. The reference cards will be distributed with the brochure, which contains more detailed background information about the different steps and guidelines. The information will also be available on the EULAR website in order to improve implementation.

A second training session is planned for patient research partners by the end of 2013 because it is felt there is a lack of participation of patients with certain conditions such as lupus, and there is a need for more people from Eastern European countries to take part.

Hopefully, it will be as successful as the first time.
**Join us for World Arthritis Day 2013**

“The Living Better, Ageing Well” – growing up and growing older with a rheumatic and musculoskeletal disease (RMD) is the topic for World Arthritis Day (WAD) 2013-2014. All sorts of exciting activities are planned for this year.

The heart of the 2013 activities will be an online competition which will invite people with or without RMDs to be creative. Send us your picture, painting, sculpture or video and create your vision of what changes could be made to improve the lives of people with RMDs over the next 30 years. We want you to picture an ideal world in the year 2043 – anything is possible and you can make it happen! More will soon be revealed on www.worldarthritisday.org

“Living Better, Ageing Well” covers the physical and mental changes that occur throughout our life, as well as all the other factors that affect our ability to enjoy an optimal quality of life. This includes access to buildings, transport, technologies, medicines and treatments; societal attitudes; the lifestyle choices we make, and more.

We will provide expert information around these key topic areas of life that are important to improving the quality of life of people with RMDs on our website, starting with a feature around “Healthy Living” talks about physical activity, nutrition and weight management, self-management and motivation, emotional well-being and more.

The “Get Active” booklet and guide features physical activity and exercise, and highlights some activities like swimming, cycling, gardening, home gym, yoga, tai chi and many more. It is available on the website and available for people to download as design template in the “Tools for you” area.

Raising awareness is one of the main goals of World Arthritis Day and it is a great opportunity for organisations, hospitals, other institutions and individuals to reach out to the public and organise exciting events to inform people about RMDs and celebrate 12 October 2013.

World Arthritis Day is growing from year to year and we hope that more than 80 countries will join us in 2013! Use our Events Map 2013 to share your plans around WAD widely to help inspire others and promote your activities widely.

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**Einar Ingolfsson**, President of Gigtarfélag, said: “We are delighted to welcome our European colleagues to Iceland. Our members are excited to learn more about the work of EULAR and look forward to exchanging experiences with the delegates from so many different countries. We very much hope that this conference will also raise awareness for RMDs among Icelandic policy makers.”

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The 16th Autumn Conference for PARE will be held between 15-17 November 2013 in Reykjavik and will be hosted by the Icelandic organisation Gigtarfélag. The overarching topic this year will be Healthy Ageing featuring the WAD theme of “Living Better, Ageing Well”.

“The Autumn Conference will see a few novelties for 2013. The official opening will be on Friday morning to make best use of the delegates’ energy. More workshops and fewer plenary talks will put a strong focus on interaction this year,” informed Marios Kouloumas, the Autumn Conference Task Force leader. “With more interactive participation in this year’s conference, the criteria for those attending has been changed to ensure that delegates’ experience and their role within their organisations is aligned to the workshop themes of campaigning, capacity building and policy work.”

The workshop topics will fall into three streams under the headings of campaigning, capacity building and policy. Topics will range from developing and delivering self-management courses to looking at the political implications of healthy ageing, standards of care and co-morbidities and the support organisations can give to older people with rheumatic and musculoskeletal diseases (RMDs). Other related topics will include how to build networks for young people with RMDs, and how to recruit and manage volunteers.

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**Einar S Ingolfsson** (front left), President of Gigtarfélag, and his team (from left) Lena Hreinsdóttir, Emil Thoroddsen and Kristín Magnúsdóttir welcome the Autumn Conference in 2013
PARE has always put the national member organisations at the heart of its activities according to Maria Batziou, Chair of the EULAR Standing Committee of PARE. “This is even more reflected now in EULAR’s new Strategy Vision 2020,” said Maria.

One of the ways the EULAR Standing Committee of PARE has supported national organisations of people with rheumatic and musculoskeletal diseases (RMDs) is through its Country Visits – where a EULAR delegation of scientific and PARE representatives have supported member organisations in arranging and attending high level political events that have been very successful.

Here, Breakthrough looks at some recent examples of this successful co-operation.

**In Bulgaria**

During EULAR’s visit in June 2012, the Bulgarian Organisation for Patients with Rheumatic Diseases organised a round table to which decision-makers like the Bulgarian Ombudsman Mr Penchev, the Secretary of the Bulgarian Medical Union Mr Lenkov and the Chairman of the Centre for Protection of the Rights in Healthcare Mr Katarov were invited. MEP Ivailo Kalfin also attended and voiced his support for the organisation’s goals – a better life and better treatment for those affected, not only locally but also at European level.

This Member of the European Parliament signed the Brussels Declaration and waved for the World Arthritis Day campaign. The presence of EULAR representatives at this meeting confirmed the organisation’s status as a recognised member of the PARE Standing Committee, serving also to illustrate how other people with RMDs in Europe cope with their problems.

They also shared their information and experiences, convincing the audience of the importance and impact of RMDs.

The final review of the round-table discussion resulted in the development of a draft Serbian Strategy and National Action Plan to fight RMDs.

**In Israel**

David Magnusson, incoming Chair of the Standing Committee of PARE, participated in a visit to Israel in October 2012. Talking about the visit, he said: “INBAR arranged an impressive programme for EULAR. It was a great opportunity to meet key Israeli stakeholders and I was delighted at the positive results.”

It was indeed a busy programme which included an important meeting with the Director General of the Ministry of Health of Israel, Prof Ronni Gamzu, in which the team stressed INBAR’s efforts to increase rehabilitation treatments for people with RMDs in Israel, as well as how having additional treatments could prevent deterioration of the patient’s condition.

It was a great success: the main outcome saw the Ministry acknowledging the future inclusion of the anti-CCP (anti-cyclic citrullinated peptide antibody) examination in the Israeli basket of health services.

**In Serbia**

In February 2013, a high level EULAR delegation visited Serbia to assist the Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS) and the Rheumatology Association of Serbia (RAS) in their work.

A round-table meeting gathered senior Serbian Government officials, and other key public stakeholders, and was followed by the signing of the Brussels Declaration – a focus of extensive media coverage. At that time, the Secretary General of the Ministry of Health, Dr Perisa Simonovic, pledged support for the establishment of early arthritis clinics, training for primary care doctors, the establishment of a rheumatology commission to promote a new national strategy for RMDs, and increased investment in biologics and infrastructure.

The final review of the round-table discussion resulted in the development of a draft Serbian Strategy and National Action Plan to fight RMDs.

These events and the positive statements issued by the Ministry of Labour, Employment and Social Policy, and the Ministry of Education, Science and Technological Development, as well as the support showed by the Union of Employers, all signal a new approach to RMDs in Serbia.
The Finnish Rheumatism Association has 161 local branches and more than 42,000 individual members. It works to promote high quality care, rehabilitation, and quality of life for people with rheumatic and musculoskeletal conditions (RMDs). The prevention of RMDs has always also been an important part of our activity.

Knowledge against pain
Musculoskeletal conditions involve sensations of pain, which can vary in how noticeable they are. Expressing and describing pain can sometimes be very difficult. Pain cannot be verified in the laboratory, but someone who has also experienced pain can act as an interpreter. The Association has prompted its local branches to organise peer group meetings, whose purpose would be to relieve pain by means of music, dance, yoga, painting, writing, handicrafts, art therapy, relaxation exercises and other teamwork, instead of focusing on accounts of pain experiences. This year, lectures for the general public will be organised around Finland under the same topic.

Motion is medicine
By far the most popular activity of our local branches is fitness exercise. Annually, they organise almost 500 fitness exercise groups with more than 6,000 regular participants. A large-scale operation such as this is only possible with a great number of volunteer workers.

The most popular fitness sport is warm water aerobics in groups, followed by Nordic walking or walking. For a couple of years, the Finnish Rheumatism Association has launched Musculoskeletal Service Stations, a small-scale test of musculoskeletal fitness, in various events around Finland. Thus far, 6,000 Finns have visited them to check their balance, flexion of lower back and functioning of upper arms.

Diagnosis-specific contact person network
In collaboration with healthcare service units (a health centre or an outpatient department), the Finnish Rheumatism Association is developing an RMD care pathway to make them extend as far as the peer group activities of the local branches. If a healthcare unit is unable to guide a recently diagnosed person to a local branch, the nationwide diagnosis-specific network’s contact person comes to the rescue. They will be the first contact for people confronting a disease and encourage the patients to participate in the Association.

Getting active in Finland
By Lea Salminen, Director

The Flemish umbrella-organisation ReumaNet recently presented an action plan for 2013 – a year in which there will be multiple actions under the motto “Rheumatism? Action!” With this campaign, ReumaNet wants to highlight the vital role of physical activity and the fact that there’s still a lot to be done. Here is an overview of our plans.

World Arthritis Day: The highlight of the year will be 12 October. There will be action in various Flemish hospitals and a “patients’ day”, where participants will get the latest news on rheumatic diseases during lectures and workshops.

Guidelines on biologics: In 2012 ReumaNet launched an information file on biologics. In collaboration with rheumatologists, ReumaNet will expand this dossier in 2013, with practical guidelines for the use of biologics, such as: What should I do if I want to travel abroad? What if I have an allergic reaction?

Website renewal: We have been working on the renewal of the ReumaNet site, which went online in the spring of 2013, making it easier for visitors to find their way to the information and/or the patient group that they are looking for. ReumaNet will also create a separate and interactive site for kids and teens, which will be launched in the autumn.

Survey and new initiatives on physical activity: We want everyone to get physically active. ReumaNet wants to draw up a report on the movement pattern of patients by calling on members to participate in a large-scale survey. Based on the results, new initiatives will be launched.

There is more: an overview of the local regulations and provisions in social security regarding long-term disability, consultation moments for parents-to-be with a rheumatic and musculoskeletal disease (RMD) or a child with a rheumatic condition, training on patient participation in scientific research, and a campaign on work.

Follow us on www.reumanet.be
Spotlight on partner organisations

Eumusc.net entering final stage

By Babette Anhalt, Communications Officer, EUMUSC.NET

Eumusc.net is a three-year project that aims to raise, harmonise and improve quality of care, and enable equity of care of rheumatic diseases and other musculoskeletal conditions across Europe. The eumusc.net project is now entering its final stage and will finish its work by June 2013.

During the EULAR Congress in 2012, Prof Antony Woolf held a press conference which focused on one of the major obstacles in achieving equity of care across the EU Member States – the lack of comparable data relating to musculoskeletal conditions. The collection and analysis of comparable data in each Member State will enable benchmarks to be set and progress towards equity of care to be measured. So a key objective of eumusc.net has been to provide supporting evidence at a national level that highlights the impact of musculoskeletal conditions in terms of health, social, employment and economic measures. The results of this work are published on the eumusc.net website.

In addition, eumusc.net developed a set of core indicators in the form of an assessment tool, which enables each Member State to measure the burden of musculoskeletal conditions in their own country relative to others, and to identify areas for improvement.

In order to understand the quality of healthcare being provided, it is necessary to understand the standards of care citizens should expect and to be able to measure the extent to which healthcare providers deliver those standards. To this end, eumusc.net developed Standards of Care (SOC) for Rheumatoid Arthritis (RA) and Osteoarthritis (OA), and Health Care Quality Indicators (HCQI) relative to these standards. Wide adoption of the same Standards of Care will enable comparisons to be made between each of the Member States and will support efforts to achieve equity of care.

The use of HCQI raises awareness among individual rheumatologists and practices regarding gaps in their service. In 2012 eumusc.net identified barriers and facilitators to the implementation of the Standards of Care through an online survey and qualitative research. The results of the survey were presented at the EULAR Congress in Berlin last year.

Based on the work that has been done, in 2013 eumusc.net will provide and disseminate a set of recommendations to ensure that people with OA and RA receive optimal care. The recommendations have a clear call to action: Start Measuring, Compare Results, Set Goals, Work to Improve.

After June 2013 the eumusc.net project will officially be finished. We hope the tools provided by eumusc.net will enable patient organisations, health care professionals and policy makers throughout Europe to keep up the good work and strive for equity for all people living with musculoskeletal diseases across the EU Member States.

It’s in your hands now!

Tools for you

The eumusc.net project website at www.eumusc.net provides helpful information in the area of rheumatology and rheumatic and musculoskeletal conditions. If you are a person with a musculoskeletal condition, a health professional or a decision-maker, you can subscribe to their newsletter via eumusc.net@cornwall.nhs.uk and receive updated information. Examples of what you will find on the website include:

- EU Member State factsheets with detailed information about the health, social, employment and economic impact of musculoskeletal conditions across each Member State
- a report on the impact of musculoskeletal conditions across the Member States (full version and summary versions available).
- the Standards of Care for Rheumatoid Arthritis (RA) and Osteoarthritis (OA), which serve to identify core sets of patient-centred standards of care that individuals across Europe with OA and RA should be receiving from their healthcare providers
- Health Care Quality Indicators for Rheumatoid Arthritis (RA) and Osteoarthritis (OA).

EULAR Secretariat

Birte Glüsing (Project Manager) & Florian Klett (Project Co-ordinator), Seestrasse 240, 8802 Kilchberg, Switzerland
Tel: +49 (0) 228 9621283 and +41 (0) 44 716 3035, Fax: +41 (0) 44 716 3039
Email: Birte.Gluising@eular.org and Florian.Klett@eular.org
Website: www.eular.org

Barriers in Oslo 2012

EULAR European Congress on Rheumatology

EULAR supports the BJD: www.boneandjointdecade.org