Strengthening links

EULAR President, Maurizio Cutolo talks about recent successes and his vision for the next 12 months

What other priorities do you see in this second year of your EULAR Presidency?

Maurizio: The most ambitious targets in the EULAR Strategic Plan 2013-2017 have been defined by previous leaders. Perhaps now there is the possibility of achieving all of them. However, one of the priorities I would continue to support is productive co-operation with all other major world-level rheumatology leagues, including North America’s, American College of Rheumatology (ACR) and the Asia Pacific League of Associations for Rheumatology (APLAR). At present I also serve as Chair of the Executive Committee of the International League of Associations for Rheumatology (ILAR). Recently we have introduced the “EULAR Symposia” into the annual meetings of major world-level Rheumatology Leagues. This has been achieved with the African League of Associations for Rheumatology (AFLR), the Plan American League of Associations for Rheumatology (PANLAR), the Asia Pacific League of Associations for Rheumatology (APLAR) and, of course, the ACR.

I do not deny this implies a lot of work, but the links now seem really strong and productive. I am eager to introduce new common interests and to share guidelines between leagues for important emerging topics – such as what biosimilars can propose; the very early diagnosis of RMDs through use of sensitive biomarkers and instrumental tools such as joint sonography; and, most importantly, to optimise the use of low-dosage, long-term glucocorticoids.

It is a year since the EULAR Strategy was launched. How is it helping to deliver better outcomes for patients?

Maurizio: Patient associations have built a wonderful system for updating themselves on diagnostic and therapeutic advances, and also linking almost all European countries with an official representative within EULAR. The new EULAR Strategy has certainly helped and supported this expansion and efficient networking. On the other hand, contributions by patient associations in terms of spreading the “RMD culture” is unmistakable. It is crucial to achieve successful contact with health authorities and EU decision makers.

You attended your first EULAR Autumn Conference in Iceland last year. What learning did you take back home?

Maurizio: The interest participants had for all sessions was exceptional. My impression was that people with RMDs benefit a lot from such kind of meetings, since they can exchange different experiences with experts and between themselves in a friendly atmosphere. The translation of complex medical concepts related to the pathogenesis and mechanisms of major RMDs in easy-to-understand talks was particularly well accepted by patients during the entire conference.

The suggestion for the future is to help optimise the lifestyles of people with RMDs by reporting mainly evidence-based aspects of rheumatic diseases during patient sessions, alongside practical suggestions. This could include lessons on “best diet” and physical exercise.
Looking to the future

PARE Chair, Diana Skingle, talks to “Breakthrough” about her aims during her term of office and highlights the topics on which she will be focusing

The EULAR Standing Committee of PARE already has a very wide-ranging suite of successful programmes and projects. Nevertheless, the new EULAR Strategy 2013-2017 gives us the framework to go even further. In the coming years, PARE will focus on Strategic Objective 2 – Education, Strategic Objective 4 – Advocacy, and Strategic Objective 7 – National Relations.

We will look at better ways to share good practice – no good idea should go to waste, and there is so much innovative work being done by the EULAR member organisations. Linked to this, we will also explore how to make the vast array of existing PARE educational materials more easily accessible.

Our aim is to ensure that people with rheumatic and musculoskeletal diseases (RMDs) can acquire the skills and knowledge to make better decisions about managing their condition, and are able to realise their full potential. At the same time, national organisations need up-to-date information and tools to enable them to carry out their campaigning roles effectively.

As you probably know, people with RMDs are now increasingly being involved in research projects at all stages. Our Patient Research Partners training programme has been incredibly successful and I look forward to ensuring that it is firmly embedded into EULAR’s infrastructure. We will continue our traditional programmes such as World Arthritis Day and the Edgar Stene Prize competition, but will streamline them and make them more relevant to new audiences.

I am delighted to say that the views presented in the recent Youth Project survey have given young people with RMDs a distinct voice in EULAR for the first time. We now have to work to ensure that there is a strategy and mechanism for their views to be incorporated into all of PARE’s work, and for young people to be able to participate as fully as they wish. They are the future leaders of PARE and we must invest in them, and give them the skills and confidence to take up these roles.

Of course, none of these aims will be achieved without the total dedication and commitment of the PARE Board members, and the extraordinary talents and hard work of members of the EULAR Secretariat.

I would like to pay tribute to these exceptional people. It is a great honour to be part of such an inspirational team.
Introducing the EULAR Standing Committee for Epidemiology and Health Services Research (SCEHSR)

by Deborah Symmons (Chair) and Loreto Carmona (Past Chair)

This committee comprises representatives from all European countries, nominated by their national rheumatology societies. Together, the representatives are interested in gaining more understanding of the total burden of rheumatic and musculoskeletal diseases (RMDs) throughout Europe and how this varies by country, region and ethnic groups.

Over the last few years, a EULAR-funded project called eumusc.net has brought together all the available information about patterns of RMDs in Europe, including information about days lost from work and healthcare professional workforce availability country by country. This is now available on the website www.eumusc.net – it is well worth a visit if you are interested in the facts and figures of RMDs. The completion of the eumusc.net project was marked by a special meeting at the EU Parliament last October.

Going forward, the work of this group will be covered by the EULAR Study Group on Public Health, which comes under the umbrella of SCEHSR. This study group will report on the year’s activities and its future plans at the EULAR Annual Congress in Paris.

The members of SCEHSR are also interested in understanding risk factors for the development and outcomes of RMDs. These also may vary by country and region. In the field of health services research, members work to try to understand how best to deliver healthcare services to patients with a variety of healthcare systems. EULAR provides a useful forum in which to discuss the results of these studies and try to learn from best practice and outcome.

SCEHSR has another study group which focuses on registers and observational drug studies (EULAR RODS). When biologic therapies were first introduced early this century, it was felt important to set up registers to study their long-term safety. Many countries established such registers – the largest are in the UK, Sweden, Germany and Spain. EULAR has been keen to help new national registers to set up and to ensure that the way that data is collected by the different national registers is similar. This will help to combine results between registers when studying rare events.

In November 2013, a second workshop was held by EULAR RODS in Prague. This was attended by over 160 delegates including representatives of the pharmaceutical industry. There were over 20 keynote speakers as well as opportunities for discussion and debate. The group plans to hold a third workshop towards the end of 2015 and will continue to work on collaborative projects in between.

SCEHSR has also put together a library of Outcome Measures, many of which have been translated into multiple languages. These are available for clinicians to use to monitor the progress of their patients or for researchers to use for standardised assessments in clinical studies and trials. A couple of years ago EULAR commissioned some new research to fill some of the gaps in assessing RMDs. These projects are due to come to completion over the summer 2014 and we look forward to hearing the results at the 2015 meeting.

Introducing the Standing Committee of Paediatric Rheumatology

by Prof Alberto Martini, Chair of the Standing Committee

The mission of the Paediatric Rheumatology Standing Committee of EULAR is to improve the care of children with rheumatic and musculoskeletal diseases in Europe. It takes advantage of the close collaboration, implemented in recent years, between EULAR and the Paediatric Rheumatology European Society (PReS). This strict collaboration ensures a potent synergy and avoids duplication of efforts.

The current major common effort is the implementation of an online course in paediatric rheumatology. It will consist of 10 separate modules and will be available later this year. Totally run through the web, it is designed to last for nine months. The aim is to provide fundamental knowledge about childhood rheumatic diseases to paediatricians with an interest in paediatric rheumatology, or to rheumatologists with an interest in paediatrics. It will be particularly useful for those countries in which the knowledge of paediatric rheumatology is not widespread.

Another current task of the Standing Committee is to provide recommendations on how to manage the transition from childhood to adulthood for those patients with a paediatric rheumatic disease in whom the disease persists into adult age.
Shaping the future – insights into the work of the EULAR Standing Committee of Health Professionals

By Vice President Christina Opava

Christina H Opava was born in southern Sweden and is a professor in physiotherapy at Karolinska Institutet, Stockholm and has been Vice President of EULAR Health Professionals since June 2013. Her work specialises in physical activity and health in rheumatic disease.

The Health Professional (HP) Standing Committee is chaired by nurse Susan Oliver from the UK with the support of the Past Chair, Dr Thea Vliet Vlieland from the Netherlands, in collaboration with me as the new HP Vice President. Another important committee member is Dr Annette Ladefoged de Thurah, who is the HP representative on the EULAR Scientific Programme Committee.

While Susan Oliver had already been involved as Chair-elect for one year, although very honoured, I initially felt quite confused after my election last June. The summer is a very busy time with preparations for planning the following year’s EULAR Congress programme and the compilation of project proposals. However, with the support and guidance of Susan and Thea, I made it! I am now feeling a little more confident in my new role.

The three tactical objectives chosen for HPs from the EULAR 2013 – 2017 Strategic Objectives are to increase the quantity and quality of HP-led research projects and strengthen patient participation; to strengthen education for patients and HPs by developing tailored materials and improving access; and to develop and implement a communication and PR strategy to address the individual needs of patients, physicians/researchers, HPs and corporate members.

The new HP scientific sub committee is instrumental in improving research and had a very productive meeting in December in Stockholm. During my time in office as VP, I am looking forward to promoting some of the ideas that came out of this meeting. We also look forward to more collaboration with PARE as regards patient participation in research.

As we are sharing key leading responsibilities between ourselves, Susan and I were very happy that Thea accepted the role of leading the HP educational sub committee with responsibility for establishing educational initiatives in order to fulfil our second tactical objective. We have great hopes for excellent educational activities to come. Education of HP clinicians throughout Europe is of the utmost importance for the best possible care of people with rheumatic and musculoskeletal diseases (RMDs).

The EULAR scientific branch has 45 country members and PARE has 36, but HPs have only 17 members so far. As to the third tactical objective then, we will focus on increasing the number as well as the breadth of HP member countries. We were thus happy that the Executive Committee approved our proposal for an extension of our membership campaign and look forward to welcoming new HP members, hopefully later this year.

Another approved HP project is the initiation of closer collaboration with our American colleagues in the Association of Health Professionals in Rheumatology. We have already been attending each other’s conferences for several years and had informal discussions on possible collaboration. In connection with the Paris congress, we have set aside time for discussions on how to formalise our work together, looking for some ideas that can result in defined projects. We hope this will be for the good of people with RMDs on both continents.

Although EULAR’s HPs are committed to the promotion of team work involving different professional groups, it is also important to improve and implement evidence-based knowledge in each of the groups for better team outcome. We are thus happy about the great interest in the established study groups of nurses, occupational therapists, physiotherapists and psychologists that now have their own, very well attended, meetings at the yearly congresses.

Our collaboration with PARE is good. For several years I have been a member of the World Arthritis Day task force and I am now also part of the planning committee for the EULAR Autumn Conference of PARE.

I think that collaboration with PARE is key to success for the EULAR HPs and I look forward to much more of it during the years to come.
Bienvenue à Paris!
France hosts EULAR Congress 11-14 June 2014

After a successful congress in 2008, this is the second time Paris will open its doors to welcome the Annual European Congress of Rheumatology from 11 – 14 June 2014. The beautiful city is ready to receive more than 14,000 expected participants to this unique arena for the exchange of scientific and clinical information.

Marios Kouloumas, 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). He said: “With the input of the Standing Committee of PARE and the Task Force I am confident that we have managed, once more, to put together a stimulating and diversified programme which will also be attractive for health professionals to attend.”

“Our topics this year cover daily life issues such as healthy food and travelling, show successful examples of political campaigning, demonstrate the use of latest technology in the field of RMDs, and also focus on providing the latest information on the hot topics of orphan drugs and biosimilars.”

Diana Skingle, Chair of the Standing Committee of PARE, added: “We are delighted that many abstracts have been received again this year and we would like to thank all the submitters and the organisations very warmly. For the first time ever, 2014 will see EULAR awarding the best PARE abstract during the Opening Plenary Session on Wednesday 18.45 – 20.00.” PARE dedicates this first award in memory and honour of David Magnusson, who tragically passed away in October 2013. David was Chair of the Standing Committee of PARE at the time.

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 logistic details needed for finding your way around the congress venue, as well as offer 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 2014 EULAR Stene Prize booklet as well as many other recent publications. The Booth will be staffed by experienced team members who are all excited and looking forward to their time there.

Just next to the PARE Booth, the PARE Posters will be displayed from Thursday to Saturday. Paris will see the first occasion where there will be two official PARE Poster Tours – on Thursday and Friday. If you would like to join for one of the tours, please don’t forget to register officially on the day – places are limited!

If, at the end of the congress, you find you were not able to cover all you had wished to, you can always attend the PARE Highlight Session. Here you will be given an overview of the learning taken from the congress and its outcomes from the perspective of health professionals and rheumatologists, as well as the first feedback from PARE delegates.

Michaela Stoffer, an occupational therapist from Austria, will be representing Health Professionals in Rheumatology, and Prof Loreto Carmona from Spain will present the key points of the scientific programme on behalf of the rheumatologists. The PARE delegates will be invited to comment during this session and give their live feedback and impressions from the past days in Paris with the audience.

The PARE Programme

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<th>Day / time</th>
<th>Session title</th>
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<tr>
<td>11 June 13.30 – 14.30</td>
<td>Pre-conference outlook</td>
<td>PARE Session</td>
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<tr>
<td>11 June 15.00 – 16.30</td>
<td>Food as therapy – supporting healthy choices</td>
<td>Joint Session</td>
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<tr>
<td>11 June 17.00 – 18.30</td>
<td>Political Campaigning</td>
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<td>12 June 10.15 – 11.45</td>
<td>I-Patient – the role of smart decision making</td>
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<td>12 June 13.30 – 15.00</td>
<td>Don’t let the economic crisis go to waste</td>
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<tr>
<td>12 June 15.30 – 17.00</td>
<td>What’s New: Latest advances in treatment and management of RMD</td>
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<td>12 June 15.30 – 17.00</td>
<td>Patient’s perspectives in rheumatological outcomes</td>
<td>Joint Session</td>
<td>Amphi Bordeaux</td>
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<td>13 June 10.15 – 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>13 June 13.30 – 15.00</td>
<td>Healthy Ageing I – growing up with an RMD</td>
<td>PARE Session</td>
<td>Studio A</td>
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<tr>
<td>13 June 15.30 – 17.00</td>
<td>Healthy Ageing II – growing older with an RMD</td>
<td>PARE Session</td>
<td>Studio A</td>
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<tr>
<td>14 June 08.30 – 10.00</td>
<td>Facilitating a normal life – easy travelling for people with RMDs</td>
<td>Joint Session</td>
<td>Studio A</td>
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<tr>
<td>14 June 12.00 – 13.30</td>
<td>Peer support in chronic diseases</td>
<td>PARE Session</td>
<td>Studio A</td>
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<tr>
<td>14 June 12.00 – 13.30</td>
<td>Patient education for people with inflammatory rheumatic diseases</td>
<td>Joint Session</td>
<td>Amphi Havane</td>
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<tr>
<td>14 June 13.45 – 14.45</td>
<td>PARE Highlight Session</td>
<td>Highlight Session</td>
<td>Studio A</td>
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The second semester of 2013 and the beginning of 2014 have been a very exciting and successful period for EULAR EU Affairs activities. The conclusion of the eumusc.net project and the organisation of its final conference, the organisation of two meetings of the European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs), and the adoption of important EU initiatives are among the most important highlights. In addition, EULAR has developed and adopted a five-year EU Affairs Strategy, which is expected to reinforce and guide EULAR activities in this area.

EU Highlights
By the end of 2013, two important policy developments took place at the EU level.

First, the EU adopted the legislative text of the Horizon 2020 Research Framework Programme. Horizon 2020 will increase the amount of funds for research and innovation for the coming seven years. Unlike the texts of previous research framework programmes, Horizon 2020 makes explicit reference to RMDs in two of its main legislative texts. Although the approach of Horizon 2020 is not to prioritise any disease area, being mentioned in these documents may be considered as recognition of the relevance of these diseases and the need to invest in research and innovation in this area.

Second, the European Commission submitted the “Final Report of the Reflection Process on Chronic Diseases” to the EU Council. One of the important aspects of this report to our community is that RMDs are explicitly acknowledged as one of the major chronic diseases affecting the European population. As this document is expected to guide future Commission initiatives in this field, we think it is important that the Commission recognises the burden of RMDs and the possible contribution of our community to the implementation of chronic disease initiatives.

eumusc.net project and conference
2013 saw the conclusion of the eumusc.net project (www.eumusc.net). The aim of this three-year initiative (which was co-sponsored by EULAR, and undertaken with the support of the European Commission) was to raise and harmonise the quality of care and enable equity of care of RMDs across EU Member States.

To this end, the project developed standards of care for the main RMDs as well as methods and tools that will allow Member States not only to measure the burden of RMDs in their own country, but also the quality of care that people with RMDs receive.

In order to present the final results and recommendations of this initiative, EULAR organised the conference “Chronic diseases and health care delivery 2020: The challenge of rheumatic and musculoskeletal diseases. Findings, lessons and perspectives from the eumusc.net project”. The event was held at the European Parliament (EP) and at the Thon Hotel EU on 17 October 2013.

It was hosted by Paul Rübig, Member of the European Parliament (MEP) from Austria, and got the support of the Lithuanian Presidency of the EU.

The Conference was an excellent opportunity to present and discuss the evidence collected by eumusc.net that proves that RMDs are one of the most burdensome chronic conditions affecting European societies. It was also a good opportunity to raise awareness of the need to implement concrete actions against these diseases.

About 120 participants from 30 countries attended the event, including representatives of the European Commission, the European Parliament, the EU Council, the World Health Organisation, a number of patient organisations, scientific societies and health professional associations, and other stakeholders.
European Parliament Interest Group on RMDs

In its capacity as Secretariat of the European Parliament Interest Group (IG) on RMDs, EULAR organised two meetings of the Group over the last six months. The first one took place on 16 October 2013 and focused on “New EU Data Protection Legislation: Consequences for health research”.

The aim of the event was to discuss the new regulation on data protection that was going to be voted on a few days later by the EP Committee for Civil Liberties, Justice and Home Affairs (LIBE). The relevance of this new regulation is that it may hinder health research activities, since – among others – the LIBE Committee’s amendments to the original proposal would impose rather restrictive conditions for the use of patients’ data in research. The event was hosted by MEP Jim Higgins (Ireland) and MEP Takis Hadjiyiorgiou (Cyprus), and saw the participation of the European Commission and representatives of more than 20 organisations.

The second meeting took place on 18 March 2014, and focused on “What EU Public Health Policies for 2014-2019? The EU contribution to public health in recent years and the challenges for the next Parliamentary and Commission terms”. As this was the last of the 13 IG meetings of the current Parliamentary mandate, the aim was to look back at the past years of EU public health policies and discuss the added value and lessons learned from main EU initiatives.

Representatives of the European Commission, the Cyprus government, the European Public Health Alliance and the Maastricht University presented their views and opinions. Neil Betteridge, EULAR International Liaison Officer, Public Affairs, presented the RMD community perspective and recommendations. In addition, the meeting also aimed to analyse the contribution of the IG to the activities of the Parliament since 2009. Sören Haar, Head of the EULAR Brussels Office, presented a preliminary assessment.

Based on feedback from MEPS, speakers and participants as well as on information on the implementation of the IG, the preliminary assessment showed the success of the Group in terms of the relevance of the issues addressed, the quality of both speakers and participants, and the results achieved.

MEP Edite Estrela, Chair of the IG, highlighted the quality and the important contribution of the IG and called on the new Parliament to continue with this Group. She also thanked EULAR for its excellent work in implementing the IG.

EULAR EU Affairs Strategy

The EULAR EU Affairs Strategy was adopted by the EULAR Executive Committee in September 2013. This document lays down the strategic lines of the EULAR EU Affairs activities for the next years in line with the EULAR Strategic Plan 2013 – 2017.

Despite current developments in EU policies, the RMD community still expects more concrete results by policymakers in some areas. Specifically, this is the case with research (e.g., adequate support to research activities); public health (e.g., actions to improve access to early diagnosis, treatment and care); social policies (e.g., actions to facilitate the integration of people with RMDs in work and social life); and with disability issues (e.g., more specific disability legislation).

In order to raise awareness of the need to further implement concrete actions against RMDs, EULAR is seeking to increase its advocacy capacity over the next few years. To this end, the Strategic Plan 2013 – 2017 establishes “Advocacy” as one of eight Strategic Objectives.

The EULAR EU Affairs Strategy provides more detail on how this objective will be achieved. It identifies advocacy goals in major policy areas, as well as internal goals aiming to strengthen EULAR internal advocacy capacity.

Upcoming EULAR EU Affairs activities

One of the most important initiatives during the second semester of 2014 will be the Conference Analysing how to reduce access barriers to health care for people with chronic diseases in Europe – Challenges, good practices and policy options for people with rheumatic and musculoskeletal diseases [Working title] on 16 October 2014. EULAR will organise this event in the context of World Arthritis Day.

The main goal of the conference is to raise awareness about the barriers to healthcare faced by people with RMDs and other chronic diseases, as well as to propose concrete recommendations to EU, national and regional policy-makers on how to tackle those barriers and facilitate access to quality care.

For more information on these events, visit the EULAR website (www.eular.org) or contact the EULAR Brussels Office (Brussels@eular.eu).
Edgar Stene Prize 2014
A vision of how life with an RMD could be in 2043

How will the world look in the year 2043? Will researchers have found a cure for rheumatic and musculoskeletal diseases (RMDs)? What about early diagnosis and treatment options? “It was very meaningful to read the contributions to this year’s competition as they clearly showed where people with RMDs today see the biggest challenges in their life. The wish for acceptance as full members of society plays a huge role, as well as the wish of everyone that there will be treatments available that have no side effects and work effectively,” said Diana Skingle, Chair of the Standing Committee of PARE and ex officio Jury Member.

The winner of the 2014 Edgar Stene Prize competition is Marinka Stein Due Sørensen, from Denmark. Her essay on the overarching topic “Vision 2043 – my ideal world for people with a rheumatic or musculoskeletal disease” impressed all five main Jury Members – although it was a difficult choice to make, as 17 entries competed for the Prize.

“As the 2013 winner was a Danish writer, I thought my chance of winning would be really small,” said Marinka about her success. “So I almost could not believe it when I heard the news. I am so happy and honoured that my essay has been chosen. I have never been to the EULAR congress before – or even Paris – so this is really very exciting for me”.

Marinka will present her essay during the PARE Abstract Session at the EULAR Congress on Friday 13 June between 10.15 – 11.45am in Studio A.

The winner of the 2014 Edgar Stene Prize competition, Marinka Stein Due Sørensen, from Denmark

A 2014 Stene Prize booklet containing an anthology of contributions on the exciting 2014 theme has been produced and will be available at the PARE Booth in the EULAR Village or can be downloaded from the EULAR website on www.eular.org after the congress.

YOUNG PARE – a step forward

The PARE Youth Research Project is the first and largest European study of the needs, obstacles, priorities and preferences of young people, aged between 18 and 35, with a rheumatic and musculoskeletal disease (RMD). This study has been carried out by, with and for people from the target group. The results reveal a variety of circumstances which affect the lives of young people with RMDs in Europe.

A mapping exercise showed how young people with RMDs are currently organised in different European countries. Only 22 (55%) of the EULAR member organisations of PARE have some kind of activities dedicated to young people. There is no common understanding of what “youth” is, with age varying between 0 and 55.

Based on qualitative interviews and focus groups in five countries, a European survey was organised in 18 languages. There was a response from 3,501 people, representing 41 European countries. After the responses were assessed, 2,329 enquiries were eligible for statistical analysis. A remarkable number of respondents (66%) were young people not belonging to an organisation, and many were reached through modern communication channels.

“The outcomes showed that having an RMD has a significant impact on all areas of life – education, work, social life, family life, intimacy and health care. Fatigue, pain, functional disabilities and the unpredictable nature of the disease are symptoms that many respondents experience,” said project convenor Maarten de Wit.

Talking about the disease is a huge issue in many countries, with 68% of respondents saying they prefer not to disclose their condition. The majority of respondents experienced a delay in their educational career and 95% of young people reported a significant impact on their ability to work. But there also were positive outlooks. A respondent said: “Sometimes you just need to pull yourself together and manage. It helps if you think positive and try to do as much as you can.”

The second phase of this research project will focus on building a youth strategy based on the survey findings. Concrete recommendations for action will be prepared to fully integrate the views of young people with RMDs into EULAR (PARE) strategies and activities.

The results of the research project will be presented during the EULAR Congress in Paris and feature in the session “Healthy ageing I – Growing up with an RMD” on Friday 13 June 2014 from 13.30 – 15.00.

For more information, please visit www.youngpare.org or send an email to the project coordinator Ingrid Pöldemaa at ingrid.poldemaa@gmail.com.
Get creative for World Arthritis Day 2014

Help us promote the World Arthritis Day competition and be a part of Vision 2043 to transform the future lives of people with RMDs

The World Arthritis Day Vision 2043 competition asks you to share one idea to help improve the lives of people with RMDs and create a more inclusive world by the year 2043.

All you need to do is write a short statement (in English) about how your entry will help improve the lives of people with RMDs. You can include supporting photos, videos or a soundtrack. Then upload your statement (with photo, video or soundtrack) into the Vision 2043 gallery by the competition deadline on Friday 18 July 2014.

The logo and artwork are ready for you to use. Please download our promotional pack with short guiding thoughts and examples, eg which hashtags to use #RMDs #arthritis #WAD2014 #worldarthritisday2014 and example Tweets! As for Facebook, it is explained that it is always useful to try to include a call to action and the link to the Vision 2043 page.

Check out the website (www.worldarthritisday.org/vision2043) and get creative. You can also find out more on our Facebook page and you can follow us on Twitter. Please tell your networks and spread the word!

The European winner will also win attendance to the 2014 EULAR Annual European Conference of PARE in Zagreb, Croatia.

Two runners-up will each receive Euros 50, and up to seven entries will be chosen by the Vision 2043 jury for commendation (no cash prize). Everyone can vote so make sure you tell your family and friends about your entry!

EULAR Annual European Conference of PARE 2014

Former Autumn Conference with new name

The upcoming conference in Croatia, 7 – 9 Nov 2014, will be the first one operating under the new name “EULAR Annual European Conference of PARE” after the Standing Committee was invited to suggest a new title in 2013.

“It is a new name, but the concept we successfully introduced in 2013 will stay the same. This means that delegates will again have a variety of workshops to choose from, together with lots of opportunities for networking and exchanging best practice,” said Marios Kouloumas, Vice President EULAR representing PARE and leader of the Task Force planning the 2014 event.

The Zagreb Conference will discuss topics such as rehabilitation, successful abstract writing for the EULAR Congress, the use of social media, how to help people eat healthily when having a rheumatic or musculoskeletal disease (RMD), how to support children with RMDs and their parents, and the needs of young people with RMDs.

Frane Grubisic, President of the Croatian League Against Rheumatism, and host of the conference, is eager to welcome around 120 delegates to Zagreb: “It is a unique opportunity for our members to engage with their colleagues from more than 30 different European countries,” he said. “The exchange will strengthen our national network of people with RMDs and volunteers, and inspire them to continue with this important work. It is also vital that our key stakeholders see that we are not on our own but part of Europe – even the EU. This should give us more weight when discussing cuts in the health system which threaten the quality of life of those living with RMDs in Croatia.”

Delegates at the 2013 conference in Reykjavik, Iceland
Preventing rheumatoid arthritis

by Codruta Zabalan,
EULAR Patient Research Partner

Preventing rheumatoid arthritis (RA). Would you believe it’s possible? And when? 30 years from now? 20 years from now? I daresay we might see this dream come true this decade or at least we might move closer to the concept of “prevention for RA”. How do I know that? Because a world-class research team of 13 academic partners from six European countries (Austria, Germany, the Netherlands, Sweden, Switzerland and the United Kingdom), in collaboration with three companies with an interest in developing predictive kits, together with patient research partners, are working on it within a European Union funded project called EuroTEAM.

The project started in November 2012 and its goal is to predict the onset of RA in people who do not yet have the disease. The ultimate goal is to develop treatments to prevent people from getting RA in the first place.

I was one of the patients invited to participate as a Patient Research Partner and I had a very rich experience attending the kick-off meeting early last year, a half-day of which was exclusively patient-centred. The project is complex and technical, but the lay-language material sent in advance (many thanks here to Prof Karim Raza, Deputy Co-ordinator of EuroTEAM and academic lead for patient representation) was a very useful tool, helping patients to feel totally included and prepared.

The eight reference cards offer a quick and handy overview of key elements to take into consideration when collaborating in research. Both patients and professionals have their own easy-to-use checklists. The brochure offers more detail and background information on the same matters. Patients as well as researchers have shown great interest in these documents and are happy to use them.

The Network expanded in November 2013 with another 15 trained patients. They are currently waiting to be given their first assignments.

As the project has now been finalised, actions are being taken to embed the use of the Network into the daily practice of EULAR. Patient involvement in research is not a limited process but a continuous commitment for all parties involved. In this way, we can guarantee that the voice of patients is taken into account more than ever.

Interested in the reference cards and brochure? Please contact the EULAR Secretariat at Florian.Klett@eular.org.

The Network of Patient Research Partners keeps growing

by Nele Caeyers,
Project Co-ordinator

For several years now, PARE and EULAR have invested in a strong network to guarantee the patient’s voice in rheumatology research. The project has come to an end, but the work is only just beginning.

Since the publication of the “EULAR Guidelines for Patient Involvement in Research”, a lot has happened. The first group of patient research partners was trained in 2010, and all 15 participants of this Network were closely involved in several projects throughout Europe.

Soon, though, it was clear that the collaboration between patients and researchers was not always a success. Both parties needed guidance on how to optimise this unique partnership. A thorough evaluation among patients, as well as task force leaders, led to the publication of a set of reference cards and a brochure “Patient Involvement in Research – A Way to Success”.

For more information please visit www.team-arthritis.eu

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Reaching out to minority groups and successfully engaging volunteers

A Knowledge Transfer project between Israel and Russia

INBAR (Israel) and NADEGDA (Russia) participated in the 2013 Knowledge Transfer programme offered by the EULAR Standing Committee of PARE.

The project’s objectives were to:
• increase the number of members and volunteers of NADEGDA using INBAR’s successful strategy in Israel as basis
• grant INBAR with a means of reaching out to their growing Russian and Russian-language membership, to better meet their needs and to overcome the language barrier.

The project was divided into two phases. A Russian delegation visited Israel from 22 – 30 April 2013 and got to know how INBAR manages their members / volunteer network. They learned about recruiting, motivating and managing members and volunteers, as well as training volunteers, their placement, monitoring and evaluation. Based on what they learned in Israel, the Russian representatives developed a concrete action plan to put into practice in the area of volunteer recruiting and membership management in Russia.

Then an Israeli delegation went to Russia from 14 – 19 May 2013. They got information about the health situation in Russia, the centralisation of care in Moscow and lack of specialised care services in the rest of the country. They were informed about the lack of patient support and about the strong stigma that is attached to rheumatic and musculoskeletal diseases (RMDs), often leading to family disintegration.

The situation of people at work was also approached, and they were informed, that due to the lack of government benefits for illness, people with RMDs had to keep working to survive even if greatly debilitated. Disclosure is strongly avoided in Russia.

All this knowledge permitted the delegates to better understand the Russian situation and mentality, so that a tailored approach could be planned in order to better reach out to the Russian population in Israel in the future.

Are you inspired?
Would your EULAR member organisation of PARE like to participate in the Knowledge Transfer Programme? More information can be found on www.eular.org

NRAS Scottish Campaigns Network

by Sheila MacLeod, Chair Scottish Campaigns NRAS

Health is a devolved matter in the UK, so rheumatoid arthritis (RA) services are configured differently in Scotland from other parts of the country. As the voice for people with RA, the National Rheumatoid Arthritis Society (NRAS) wants Scottish patients, their families and carers to be fully involved in public policy discussions.

NRAS, therefore, launched a Scottish Campaigns Network in 2012 to empower volunteers to undertake more advocacy with politicians, civil servants and healthcare professionals, and to promote understanding of the key opportunities to improve care. NRAS recruited to Scottish Ambassadors through our membership team and our Scottish medical advisers. Ambassadors were given two training sessions in Maidenhead and Edinburgh. The first session introduced the charity’s history, aims and ethos, and the services provided through a series of meetings with NRAS staff. The second session took place two weeks later in Edinburgh and dealt with parliamentary procedure, RA-related health policy and the wider institutional landscape in Scotland.

Since the launch of the Network, the Scottish Ambassadors have been involved in a wide range of activities. For example, with support from NRAS staff, Scottish Ambassadors attended Scottish party conferences for the first time and met with high-profile politicians including the Cabinet Secretary for Health, Alex Neil MSP, and the Convenor of the Health and Sport Committee, Duncan McNeil MSP.

In addition, one Ambassador has taken on the Secretariat role for the Scottish Parliament’s Cross Party Group for Arthritis and Musculoskeletal Conditions. Another Ambassador has presented to the Group on the patient experience of living with RA and several Ambassadors have submitted case studies on their experiences of care for an audit of RA services in Scotland.

Overall, the Scottish Campaigns Network has helped to improve NRAS’s level of engagement. It has given NRAS continuous “on the ground involvement” in Scotland for the first time, expanded the organisation’s campaigning resources and demonstrated to policymakers that NRAS genuinely represents the local views of Scottish patients.

Sheila MacLeod, Chair of the Scottish Ambassadors said: “It is a pleasure to lead this enthusiastic group in such interesting and varied work. With NRAS backing and our own foothold in the distinctive Scottish political and health scene, I believe we can help make real progress for people affected by RA.”
Meeting the needs of patients: collaboration between universities and patient associations

By Margarida Espanha, General Secretary of the Portuguese League Against Rheumatic Diseases

One of the missions of universities is the transference of research knowledge created to meet the needs of society. Furthermore, students who work as volunteers while still at university can help make a difference to people’s lives. Therefore, they should be encouraged to work on a voluntary basis in patient associations to help associations offer better services to their members – namely healthcare services not affordable to people with low income.

The Portuguese League Against Rheumatic Diseases (LPCDR), with the cooperation of the University of Lisbon, endorsed two volunteering activities involving undergraduate and graduate students with local and/or academic supervision. In the first initiative, after a brief training period supervised by one volunteer member, three undergraduate nursing students were responsible for contacting all members by telephone in order to find out how they were feeling, if they had any special needs or would like to be visited at home.

Home-based exercise

In the second initiative, two students of the Master of Science in Physiotherapy course (Faculdade de Motricidade Humana / Faculty of Human Kinetics) were encouraged to deliver home-based exercise to three patients – two with rheumatoid arthritis and one with hip osteoarthritis.

Exercise is recognised as an effective non-pharmacological treatment and exercise modalities should be adapted to the affected joint, the health status of the patient, and severity of the disease. Therefore, we conducted individualised home-based exercise programmes, adequate for people with restricted mobility and autonomy.

Jeane Constantino, one of the students, said: “Attending was a great experience for me. We had empathy and trust which allowed for successful treatment. The patient had a lot of willpower, and evolution was visible session after session. Treating her became very rewarding. I was able to learn a lot from her, and this added greatly to me personally and to my academic training.”

The general objectives of these programmes were to increase range of motion, muscle strengthening and balance improvement. The programmes took place over a month and the session type consisted of a warm-up period (5 min); followed by stretching exercises (15 minutes); strengthening exercises with the aid of elastic bands (30 minutes); and breathing and relaxation exercises (10 minutes).

Evaluating effectiveness

The outcomes used to evaluate the effectiveness of the exercise programmes were: range of motion of two or more affected joints; strength of knee extensor muscles; and Patients’ Global Impression of Change (PGIC). The results showed improvements both in range of motion and strength, pain reduction (NRS) and, on average, “moderately better” change.

This type of collaboration between universities and patient associations is an excellent way to meet the needs of patients, taking advantage of research and of the willingness of students.

Yokiny Araújo, another student, said: “The experience was very enriching. It was a great pleasure to participate in this project and be one of the pioneers in this work because, besides learning a lot, I made friends for life. I would like to thank the patients for having entrusted me with their most precious possession – their bodies. I am also grateful for their confidence in trusting my capacities.”