Dear Colleagues

We finished 2014 on a high note with a tremendously successful 17th EULAR Annual European Conference of PARE in Zagreb in November. Our Croatian hosts gave us a very warm welcome and the elegant surroundings of the conference hotel put the delegates in the mood to work hard and participate enthusiastically in all the Conference workshops. Hvala!

With the re-scheduling of the PARE Conference timetable from Autumn to Spring, the 18th Conference will take place in Dublin in April 2015 (see below). This will give national organisations the unprecedented opportunity for their volunteers and staff to acquire new skills in a very short period of time. I hope that will lead to enriched organisations and exciting new national programmes and activities. Do tell us what has inspired you to make a difference. We would like to showcase your successes here in future editions of e-Breakthrough.

The plans for the PARE programme at the EULAR Congress in Rome in June 2015 are already far advanced. We hope that you will find plenty to interest you. Also work has begun on planning for World Arthritis Day 2015. We have a new agency handling the website so you will see some changes. More details in the next edition of e-Breakthrough.

I wish you and your organisations a successful and productive year ahead, supporting and enhancing the lives of people living with rheumatic and musculoskeletal diseases. I look forward to seeing many of you at PARE activities in 2015.

Making a difference by Diana Skingle, Chairperson of the EULAR Standing Committee of PARE

EULAR Annual European Conference of PARE
Dublin, Ireland      24-26 April 2015

Arthritis Ireland, host of the 18th EULAR Annual European Conference of PARE, is planning a wonderful welcome for their fellow European colleagues in April 2015 in Malahide, the beautiful seaside resort close to the city of Dublin.

The overall Conference topic will be ‘Patient centred care – taking control’. “This topic fits extremely well with some of the core activities run by our organisation, such as our self-management courses” said John Church, CEO of Arthritis Ireland. “We look forward to sharing our knowledge and best practice widely, as we understand that self-management courses are not yet available everywhere”. As in previous years, the Dublin Conference will offer a variety of workshops from campaigning to e-health, plus plenty of time for networking and exchanging experiences. There will be something for everyone!

John and his team will also use the opportunity of hosting the Conference in Dublin to raise awareness of rheumatic and musculoskeletal diseases (RMDs) with key Irish stakeholders, and to inspire the many volunteers who give their energy and free time to support Arthritis Ireland’s various activities.
This summer EULAR launched its new website for the Annual European Congress of Rheumatology (www.congress.eular.org).

The aim was to have a website, detached from the main EULAR website, with a fresh new look and user-friendly navigation, helping to provide better resources to our stakeholders. Therefore the layout has been completely redesigned - clear and simple to use, and easier to access. Whereas the teasers on the homepage focus on the most important general topics around the Congress, the top navigation menu is divided into different areas of interest. The latter again are split into different sub categories, each providing relevant information for Congress participants. Last but not least, the new Congress website is now optimized for mobiles, allowing users to access information in faster and more easily digestible bites. No more waiting for content, no more zooming in - simply tap and read, tap to call, and tap to email.

If you like our new Congress website, you will be delighted to hear that the new main EULAR website will also be unveiled soon. While the current EULAR website (www.eular.org) has served us well for many years, it is important for us to deliver a better user experience to you, bringing a more simplified way of discovering the world of EULAR. If you have any comments on the new Congress website please send them to me at caroline.desiderio@eular.org I should be very pleased to have your feedback.

Basic and translational research efforts remain essential to advance the field of rheumatic and musculoskeletal diseases (RMDs). The Standing Committee on Investigative Rheumatology seeks to enhance the knowledge about the genetic, molecular and cellular basis of RMDs, aimed at developing better prevention, early detection/diagnosis and treatment for all patients. The committee acts as an umbrella for a number of Study Groups and is composed of representatives from all European countries, nominated by the respective national societies.

The different Study Groups are essential platforms for EULAR to foster and boost research on RMDs. The Study Groups welcome any researcher or stakeholder interested in learning, collaborating, advocating and discussing specific topics or research areas. Some Study Groups have a long history such as the EULAR Study Group on Neuro Endocrine Immunology of the Rheumatic Diseases (NEIRD), the EULAR Synovitis Study Group (ESSG) and EULAR European Consensus Finding Study Group on Laboratory Investigation in Rheumatology (ECFSG). Hot and sometimes controversial areas of interest are found in the EULAR Gene and Cell Therapy Study Group (GCTSG), the EULAR Study Group on Animal Models for Rheumatic Diseases (SGAM) and EULAR Study Group for Risk Factors for RA (SGRFRA). The most recent additions to our Committee’s activities are the EULAR Study Group on Microcirculation in Rheumatic Diseases and the EULAR Study Group on Osteoarthritis. A new Study Group on Sjögren’s Disease is currently being set up.

The Study Groups typically have scientific discussion meetings during the annual European Workshop for Rheumatology Research and the EULAR Congress. In these meetings data are presented, ideas are exchanged and priorities discussed in an open and welcoming atmosphere. In addition, contacts and collaborations initiated within these Study Groups have provided a solid basis for the establishments of research consortia that have successfully applied for competitive international funding and currently perform top class research.

Basic and translational science remains essential to drive progress in RMDs. The Study Groups therefore increasingly pay attention to the different stakeholder’s needs. In particular Study Groups must include patient representatives and try hard to hear their voices and include them in the discussions. Although this participation may be more challenging for the PARE group as compared to their contribution in clinical, epidemiological and outcome research, patient ideas, concerns and questions enrich the scientific projects and boost the potential impact on society.

* Rik Lories is Professor at the KU Leuven (Belgium) and the Chair of the EULAR Standing Committee on Investigative Rheumatology
This year’s EULAR Annual European Conference of PARE was held in beautiful Zagreb, Croatia, on 7-9 November 2014 and was hosted by the Croatian League Against Rheumatism, Hrvatska Liga Protiv Reumatizma. 108 delegates from 31 countries gathered to share best practice and knowledge.

The overarching theme of the conference was “Healthy Ageing with a rheumatic and musculoskeletal disease (RMD)” focusing on: policy and campaigning; information and education; and capacity building and empowerment. The delegates had the opportunity to attend four varied workshops in addition to the plenary sessions.

Dr Frane Grubišić, Head of the Department of Adult Rheumatology, Clinic for Rheumatology, Physical Medicine and Rehabilitation, University Hospital Centre, Sestre Milosrdnice, Zagreb and President of the Croatian League Against Rheumatism was delighted with the attention that the Conference received from crucial Croatian key stakeholders. “Having the Conference in Croatia made a real difference for us and our work here – it was the perfect opportunity for us to engage with EULAR and to demonstrate that we in Croatia are part of a powerful support network. We are really excited to have been part of this and it was a great experience to host the thriving PARE community”.

For the first time, delegates were encouraged to engage with social media during the Conference, using the official Conference hashtag #PARE2014. Twitter engagement during the conference was high; 291 tweets were shared by delegates, reaching a potential audience of approximately 163,000 people. The opening addresses, presentations and panel discussion were streamed live and watched by 117 ‘unique users’. In addition, the session was made available on YouTube and by mid December had been viewed almost 600 times. It is still available – to watch it please search for the Annual European Conference of PARE or click here https://www.youtube.com/watch?v=MRK9DJt586E
In Issue 3 of e-Breakthrough in April 2013, Ingrid Kihlsten and Maarten de Wit wrote about the PARE Youth Research Project, investigating the challenges facing young people living with rheumatic and musculoskeletal diseases (RMDs) in Europe today.

The research group carried out a survey of young people across Europe and the results 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 and functional disabilities were symptoms that many respondents reported.

The next stage of this important research project is to build a youth strategy. Below, Emmi Myöhänen gives her impressions of the Youth Strategy meeting in Tallinn in October. During two exciting days, a group of 26 young people from all over Europe discussed the survey findings and provided input for the PARE youth strategy to empower youth groups in every European country, to establish an international network and to integrate the views of young people with RMDs into all EULAR (PARE) programmes and activities.

“It's a rainy Thursday evening in Tallinn. The Helsinki - Tallinn boat comes to port and people rush out, me within the first ones. I zip my jacket all the way up to cover myself from the wind and rain.

Let's see: I should take left from here to get to the city centre where the Nordic Hotel Forum Tallinn is situated.

The moment I step into the lobby of the hotel I see some familiar faces from previous PARE events. I'm also glad to see some new ones too. As I check in I realise that I really don't know what to expect: We are all gathered here for a EULAR PARE Youth Strategy Meeting. What does that even mean? What is going to come out of it? During the dinner I get optimistic. Even though the first evening is kind of tense and awkward, I know from experience that people will be completely different by Saturday afternoon.

Friday morning starts with enthusiasm. We work in a new format, and in World Café* sessions we focus on health, education, work and social life, the four aspects familiar to all young people with a rheumatic condition.

Everyone gets into these themes very quickly. Once again I notice that countries within Europe vary a lot, but still during our workshop discussions and coffee breaks we manage to educate and help each other. Someone has already done what the other one plans to do, and in this group of 26 people it is easy to connect these two parties. It seems that one of the challenges in getting European youth together is that there are no organised youth groups in many countries.

On Saturday, we focused at a very concrete level on how to establish a youth group and how to raise awareness. We also had a unique chance to hear many inspirational success stories from Ireland, Poland, Denmark and other countries to motivate and inspire us all. During these workshops I could see people’s eyes opening to new ideas and plans.

We were also challenged to write down what we would like to achieve in the future: What we want to do when we get back home and also the first step to reach that goal. I have to admit, I took the first step before my boat reached Helsinki.

It’s hard to sum all the outcomes of this great meeting, but what I can say is that the visual part of it was quite impressive: We gathered all the flipcharts and sheets we filled out during Friday and Saturday in one meeting room and put them up on the walls. It really showed that we had thought about the issues and solutions during our time in Tallinn. The outcomes in action might take longer to show but I am positive that if we keep on empowering youth with these kind of inspirational meetings, we’ll have a very well connected and organised youth network within PARE in no time.

As I stand on the deck of the Tallinn - Helsinki boat on Saturday evening, I feel enthusiastic and inspired. I’ve been to many of these PARE events before and I have to say, for me, this was probably one of the best. This meeting was more intimate and more concrete. I actually felt that people went home with concrete tips, ideas and plans of either how to establish a youth group or how to make an existing one even more solid and better. I feel like it was vital to get these young people together, and this kind of work should definitely continue in the future.*

Emmi Myöhänen

*World Café is a method for hosting large group dialogue sessions.
EULAR develops many recommendations to help health professionals make evidence-based treatment decisions. These recommendations are published in the Annals of the Rheumatic Diseases, a scientific journal for practicing rheumatologists.

However, for most people with a rheumatic and musculoskeletal disease (RMD) these publications are not accessible or easy to understand. This lack of clear information is a barrier for patients in making well-informed decisions. For this reason, EULAR commissioned the development of a dissemination guide for national patient organisations. The purpose of the guide is to provide practical suggestions for improving the understanding and dissemination of EULAR recommendations among patients in each European country.

Guide for dissemination
The guide has been developed by a task force with patient representatives and health professionals. Based on a systematic literature review, the task force formulated a set of key principles for a successful dissemination strategy. First, a dissemination plan should be written right at the start of projects that formulate recommendations. Second, patients should not only be involved in the development of the recommendations but also in developing a lay version. This lay version should be translated and adjusted to the cultural context of each individual country. Finally, a combination of traditional and innovative dissemination tools should be used to reach a wide range of patients. A paper leaflet in lay language is not enough. Patient organisations should also use Facebook, Twitter and their own events to support the dissemination of EULAR recommendations.

Piloting the dissemination guide
Before the guide is published, it will be presented and used in one of the workshops at the forthcoming PARE Conference in Dublin. We also hope that the guide will be piloted by members of the EULAR network of patient research partners who are currently involved in the review of lay versions of scientific articles, published by the Annals of the Rheumatic Diseases.
The European League Against Rheumatism (EULAR) is the organisation which represents people with RMDs, health professionals and scientific societies of rheumatology of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases. Within EULAR, the national organisations of People with Arthritis/Rheumatism in Europe (PARE) work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org

Follow EULAR and World Arthritis Day on Facebook and Twitter

The Federation of European Scleroderma Associations (FESCA aisbl.) has been unifying the goals of patient support and advocacy groups for 8 years now. An umbrella group of 24 patient organisations in 19 countries, it shares awareness-raising campaigns, information, and practical strategies, not only within Europe but in the Americas, Australia, and elsewhere.

As an initial group of 7 associations, its first task was to create a World Scleroderma Day, then a World Scleroderma Congress. Currently, a major task is to partner research projects with the World Scleroderma Foundation (WSF). Scleroderma is a rare disease, and effective research requires a wider consortium of patients than can be found in one country. It is our role to provide access to a sufficiently large base for clinical research and to spread information among patients concerning new therapies.

Scleroderma, though chronic, progressive, and incurable, often goes undiagnosed for years. We work to accelerate early diagnosis and equitable treatment, and to improve understanding of the medical and psychosocial aspects of the disease. The campaigns held in every country on June 29, World Scleroderma Day, have worked wonders in raising the profile of this obscure disease, which is often linked to other rheumatic diseases like rheumatoid arthritis and lupus. In 2014, the campaign theme was “Turning Towards the Sun,” using FESCA’s iconic sunflower, worldwide symbol of the battle against scleroderma, along with a painting by Paul Klee of flowers optimistically facing a sunny window. Alexander Klee, grandson of Paul Klee, who died of scleroderma in 1940, is the patron of FESCA and WSF, and has been very supportive of our goals, chief among which is that no-one else ever lose this fight.

For more information about scleroderma, please visit www.fesca-scleroderma.eu

The Standing Committee of PARE would like to thank all those who have contributed to this newsletter

EULAR supports the BJD: www.boneandjointdecade.org