

eular

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# e - BREAKTHROUGH

News from the Standing Committee of People with Arthritis/Rheumatism in Europe

## Inside this issue:

Patient Research Partner Network	2
Final call for London Congress abstracts	2
The Edgar Stene Prize July 2016—meet the judges	3
EULAR in Brussels—the October 2015 Conference and the European Parliament Interest Group on RMDs	4
Knowledge Transfer Programme	5
Klub Kívik Camp in Slovakia	5
World Arthritis Day 2015 and 2016	6

## Dates for your diary:

- **20 January 2016:**  
Deadline for Stene Prize national essays to reach EULAR Secretariat
- **31 January at 23.59 CET:**  
Deadline for abstract submission and bursary applications for EULAR Congress 2016, London
- **29 February:** Rare Disease Day
- **15 March:** Stene Prize 2016 Winner announced
- **15-17 April:** EULAR Annual European Conference of PARE, Sofia
- **8-11 June:** EULAR Annual Congress of Rheumatology, London

Would you like to read about your national organisation's activities in one of the next issues?

Please send your article (300 words max and photographs) to [birte.gluesing@eular.org](mailto:birte.gluesing@eular.org)

## Welcome 2016! by Dieter Wiek, Chair of the EULAR Standing Committee of PARE



### Dear Friends and Supporters of PARE

My first six months as Chair of the Standing Committee of PARE were exciting and I must say time flew by.

PARE's High 5 World Arthritis Day (WAD) campaign was a great success story again. The uploaded images, not only from Europe but from around the world, prove how we all take action and that the way we cope with our rheumatic and musculo-skeletal diseases (RMDs) is in our own hands.

At the EULAR Conference **Towards More Integrated Healthcare In Europe** in Brussels in October we presented how patient organisations have experienced the treatment pathways across borders after the European Union Cross-Border Healthcare Directive was implemented. I'd like to thank all of you who participated in our survey and thus enabled this presentation. Both the Conference and

WAD events contribute to creating awareness of the problems faced by people living with RMDs and underline the necessity to improve the quality of care.

We are looking forward to two great events in the first half of 2016. In April, the **Annual European Conference of PARE** in Sofia will offer informative and interactive workshops dealing with **Patient Centred Care**. Then, in June, PARE's programme for the **EULAR Congress London 2016** will present interesting topics and high profile speakers. As always, the patient perspective will be central.

Finally, I'd like to thank you for supporting PARE over the past year and wish you all the best for 2016.

## EULAR Annual European Conference of PARE Sofia, Bulgaria 15-17 April 2016



The Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD), host of the 19<sup>th</sup> EULAR Annual European Conference of PARE, is very excited to welcome their fellow European colleagues to Sofia, Bulgaria, in April 2016.

The focus of the Conference will, for a second year, be 'Patient centred care – taking control'. Boryana Boteva, Vice President of BOPRD, said "This topic is of high importance to us in Bulgaria and we hope for an inspirational dialogue with our present key stakeholders. So far the concept of patient centred care has not been implemented in Bulgaria. We look forward to hearing latest views from EULAR President, Prof Gerd R. Burmester, and the EULAR Vice President representing the Health Professionals, Prof Christina Opava, as well as from other colleagues sharing best practice. Currently people with rheumatic and musculoskeletal diseases (RMDs) face many challenges with regard to access to treatment in our country, and we hope that hosting this important event will raise awareness with our decision makers. We have invited our Minister of Health to join us".

As in previous years, the Sofia Conference will offer a variety of workshops, plus plenty of time for networking and exchanging experiences. There will be something for everyone!



## “It’s great to see the PRP Network growing”

by Nele Caeyers, Patient Research Partner

Since 2010, trained Patient Research Partners (PRPs) have been partnering up with researchers to add extra value to scientific projects. The EULAR Patient Research Partner Network has been growing ever since.

On 22-23 October 2015, the group gathered for a two-day meeting in Amsterdam. 27 participants reflected on the work they have done in the past years. Although all were very motivated to take on their different roles, communication and preparation within Task Forces still need some attention.

An important item on the programme was the dissemination of lay versions of EULAR recommendations. EULAR has recently decided to deliver lay versions of the existing recommendations in order to make the content available for everyone, in particular for people without a medical background. The PARE Guide for dissemination is a tool that provides practical suggestions for improving the understanding and dissemination of EULAR recommendations to patients in each European country. The guide is available for downloading from the EULAR website: [www.eular.org](http://www.eular.org)

While in Amsterdam, the PRPs made a priority list of the existing recommendations. In 2016, the first papers will be published on the EULAR website. It will then be up to national member organisations to make sure the lay versions reach all the European patients. Some countries such as Germany, Belgium and Portugal are already getting ready to start with this promising project.

The PRPs discussed in small groups how they would like to see this process grow. Not only paper leaflets but also social media will play a crucial role in spreading the information. An app could offer a lot of possibilities. Rheumatology nurses and other health



professionals are important partners in the process. They can help with the translation of the English lay versions, alongside the national scientific rheumatology organisation. Some members of the network pointed out that general practitioners should not be forgotten here.

The PRPs are ready to help out with this new development, and use their expertise in their own country and in other European countries too.

Our guest speaker, Professor Christina Opava, EULAR Vice President representing the Health Professionals, gave our PRPs extra training on searching electronic databases and critically reviewing scientific publications. Professor Rinie Geenen showed the group how he interacts with PRPs in the Netherlands during the conduct of a research project.

We had a diverse group in Amsterdam, representing twelve different countries and several rheumatic conditions. Some feedback from the participants: *“Thanks for organising! It is so important to keep the network motivated!”, “It’s good to see and talk to other PRPs, to discuss and evaluate”, “It enhances the group feeling and the feeling we are working on things together”.*

The work of the Patient Research Partner Network is not finished, but only slowly getting up to full speed. If you want to receive more information, please contact Florian Klett at the EULAR Secretariat, [Florian.Klett@eular.org](mailto:Florian.Klett@eular.org)



## Final call for London Congress abstracts!

Don’t miss the chance for your campaign/activity to be featured as an oral contribution, or as a poster, at the forthcoming 2016 EULAR Congress from 8-11 June in London! The EULAR Scientific Committee - including the PARE representatives who are responsible for the PARE programme - has worked hard to make sure that London will showcase an attractive programme with a wide range of sessions relevant for our community. We need your contributions now to showcase the variety of PARE activities

in Europe. But hurry – abstracts are only accepted as submissions direct to the official EULAR Congress website, and they must be submitted by 31 January 2016, 23.59 CET at the latest. There are also a number of travel bursaries available - so don’t forget to apply for these separately when submitting your abstract!

## The Edgar Stene Prize Jury 2016 – meet the judges

Each year, a panel of people with experience or knowledge of rheumatic and musculoskeletal diseases (RMDs) has the honour of judging the annual Edgar Stene Prize competition. This year we welcome our judges who represent the three pillars of EULAR, and who come from a number of different countries across Europe.

They are joined by the Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) and the EULAR Vice President, representing PARE who oversee the judging and offer guidance to the overall process.



**Nele Caeyers, PARE Board member from Belgium and staff member of ReumaNet, is Leader of the 2016 Edgar Stene Prize Jury**

"I am very happy with the theme of this year's Stene Prize competition. It forces you to look back at your life and your achievements. Maybe it confronts you with your limits, but even more it makes you aware of your abilities! Life is too valuable, too unique and, most of all, too short to not enjoy it to the full! I am looking forward to reading all your stories and to being inspired by them."



**Prof. Tadej Avčin from Slovenia, Chair of the EULAR Standing Committee on Paediatric Rheumatology**

"It is my great pleasure and honor to serve as a member of the Edgar Stene Prize jury panel. This year's topic is particularly important as it highlights how to overcome the burden of the disease and enjoy life to the full. Working as a pediatric rheumatologist, I observe patients during the critical period of transition to adulthood when they are especially vulnerable to possible negative effects of their disease. Successful life stories of patients with RMDs are always encouraging and inspirational for both patients and physicians."



**Kjerstin Fjeldstad, Norway, Board member of the Norwegian League Against Rheumatism**

"It is an honour to be a member of the jury for the Stene Prize. I am looking forward to being inspired by the vision applicants have for their life. This year's theme "Living with an RMD – how I take action to enjoy life to the full" gives the authors an opportunity to look at their lives and tell us how they have reached their personal goals and I very much look forward to reading their essays."



**Wendy Olsder from the Netherlands is a Board member of Youth-R-Well.com and representative of Young PARE**

"It is a great pleasure to be part of this jury. I think that the theme of this year "Living with an RMD - how I take action to enjoy life to the full" will give very different, inspirational stories. I am looking forward to reading the essays of all the different European countries. As for myself, I think I enjoy life to the fullest by not letting my illness define me. Although you possibly cannot do everything you want, you can still do a lot when making a few adjustments."



**Costas Ioulianos, Cyprus, President of cosmosrheuma+, representing the EULAR Health Professionals in Rheumatology**

"Firstly, I would like to say how proud I feel to be a member of the Stene Prize jury panel. As a clinical physiotherapist – and due to my frequent involvement with people living with RMDs – I have come to the conclusion that there is an imperative need to involve the patient in all decisions concerning them and their life. By taking part in the judging panel I am sure that I will gain a lot from the patients themselves – a fact which is the most important element towards the success of our work."



**Marios Kouloumas, EULAR Vice President, representing PARE**

"This year's topic for the Edgar Stene Prize essay competition I would say is very close to my heart. As a person living with RA for many years I know first hand how important it is to take your life back, to control your future and to live independently as well as being socially active and to participate within the society and to enjoy your life to the fullest, despite the disease. This year's competition gives people with RMDs across Europe the opportunity to share their successful story with us."



**Dieter Wiek, Chair, EULAR Standing Committee of PARE**

"When you are confronted with a rheumatic diagnosis and are seriously ill - this happened to me when I was an adolescent - you feel your whole world is breaking apart, all your plans for the future vanish, pain and despair mingle and mutually reinforce. However, life is wonderful and in spite of a rheumatic disease it is possible to live a richly faceted life. And that is exactly this year's topic. It will be great to read your very personal stories."



## EULAR in Brussels by EULAR EU Office Brussels

2015 was a successful year for EULAR in Brussels, with two prominent activities at the forefront. One of these was the annual EULAR Brussels conference that takes place around World Arthritis Day, and the other the re-establishment of the European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs). Both these events demonstrate the increased recognition of RMDs by policy-makers at EU level and will significantly contribute to improvements in the policy environment for people with RMDs over the coming years.

### EULAR conference in October

The increasing interconnection of health care systems is a key trend in the provision and use of health care services in Europe. Patients are now entitled to be reimbursed for treatments received in any EU Member State; health care providers are able to offer services across borders; and health professionals can live and exercise their profession in any EU country. However, despite important progress in the development of the single market in the health sector, these trends still face a number of challenges.

In order to discuss these issues, EULAR organised the conference ***"Towards more integrated health care in Europe: Strengthening patients' access to cross-border care and enhancing health professionals' mobility. Experiences, challenges and policy developments in the rheumatic and musculoskeletal disease field."*** The event took place on 13 October, and was hosted by Takis Hadjigeorgiou, Member of the European Parliament (MEP). Chaired by EULAR President Prof. Gerd Burmester, the aim of the Conference was to bring in the experience and opinions of the

*EULAR Vice President, representing PARE, Marios Kouloumas addressing the Conference*



RMD community to the overall debate on the increasing interconnection or even integration of health care services in Europe. In particular, the event aimed to develop policy recommendations to EU and national policy makers on how to address existing challenges in patients' and health professionals' mobility and in cross-border care.

More than 140 participants, including MEPs, high-level representatives of the European Commission and the Luxembourg EU Presidency, representatives of patient and health professional organisations, and stakeholder organisations discussed a number of relevant issues. Among others, existing trends in patients' and health professionals' mobility, the transposition of the EU cross-border Directive in Member States, the lack of adequate information on cross-border health care, the obstacles to health professionals' mobility and its potential impact on health care systems, the use of eHealth technologies, and the challenges posed by different standards of care in cross-border health care were addressed.

Speakers and participants largely agreed on the need to further develop the single market in the health care sector, removing existing obstacles to cross-border care and to the mobility of patients and health professionals.

For more information, please find the conference report, videos, presentations and pictures on the EULAR website.

### European Parliament Interest Group on RMDs

Together with several MEPs, and with EULAR as the secretariat, the Interest Group (IG) on RMDs was successfully re-launched in the European Parliament on 19<sup>th</sup> November. Already enjoying the support of several MEPs from across the EU and across the political spectrum, the initial meeting was led by the Chair Roberta Metsola MEP and Vice-Chair Takis Hadjigeorgiou MEP.

Based on recent evidence, EULAR President-Elect Prof. Hans Bijlsma provided an overview of the burden of RMDs in Europe, stressing the political and economic relevance of these conditions. He also welcomed the contribution of the IG during the

*Interest Group Chair Roberta Metsola MEP*



previous parliamentary term (2009-2014) that has led to the current recognition of RMDs as one of the major chronic diseases.

Ms Metsola voiced her strong support for policy improvement in the field of RMDs. She also emphasised her results and substance-driven approach to the Interest Group. This approach, and the support by the many MEPs who have already joined, is strongly welcome and a considerable accomplishment for the RMD community.

The IG is expected to meet three times per year and will promote different parliamentary actions. For more information, please visit the EULAR website: [www.eular.org](http://www.eular.org)



## Knowledge Transfer Programme

by Karl Cattelaens, Deutsche Rheuma-Liga

Deutsche RHEUMA-LIGA  
Bundesverband e.V.



In 2015, supported by the EULAR PARE Knowledge Transfer Programme (KTP), the German Rheuma-Liga and the Swiss Rheumaliga had meetings in Bonn and Zürich to discuss and exchange ideas about improving the skills and expertise in each organisation.

**Fundraising** The Swiss Rheumaliga has been very successful in fundraising. The German Rheuma-Liga liked their ideas, in particular their fundraising agreement between the regional structures of the organisation and their initiatives in attracting legacies. Consequently, after the meeting, the German Rheuma-Liga has decided to use the Swiss model for its own future fundraising.

**On-line shops for assistive aids** The Swiss Rheumaliga has been running a very successful on-line shop for assistive aids for many years. During the visit to Zürich in January 2015, the Swiss colleagues explained how the shop was set up, its structure, products, and its management etc. However, after considering all aspects, the German Rheuma-Liga has decided against setting up its own on-line shop. The German market and user approach is different from the Swiss, and there are also more shops already selling assistive aids in Germany than there are in Switzerland.

**Social Media** During the Bonn meeting, Deutsche Rheuma-Liga employees shared their experiences in using social media. For example, they operate a successful Facebook account and internet forum. Encouraged by this, the Swiss Rheumaliga is now going to re-launch its own sites.

Finally, the Swiss Rheumaliga and the German Rheuma-Liga also shared information about their projects and programmes for people with rheumatic and musculoskeletal diseases (RMDs), seeking synergies, and learning from each other's experiences. A full report of these successful visits can be found on the EULAR website:

[www.eular.org](http://www.eular.org)

*The EULAR PARE Knowledge Transfer Programme is designed to promote the exchange of skills and the sharing of best practice between national organisations. For further information please see [www.eular.org](http://www.eular.org)*



LIGA PROTI  
REUMATIZMU  
NA SLOVENSKU

## Klub Kíbig Camp in Piešťany, Slovakia

by Petra Balážová,  
Slovak League Against Rheumatism (SLAR)



From 5-11 July 2015 the Klub Kíbig of the Slovak League Against Rheumatism (SLAR) held a camp for children at the Hotel Magnolia in Piešťany, the largest spa town in Slovakia. Thirty members of Klub Kíbig took part including 12 children. The varied programme included activities such as swimming, pool exercises, individual exercises supervised by two university physiotherapy students, games, workshops and seminars with paediatric rheumatologist Dr Košková and remedial teacher Dr Stupková. The event marked the 17<sup>th</sup> Anniversary of Klub Kíbig.

The activities were not mandatory but each day almost everyone at the camp participated as they were so relaxed and well-prepared. Participants could write down their feelings that were then collected at the end of the camp, compiled and shared on our website: [www.mojareuma.sk/zivot-s-reumou/pocity.html](http://www.mojareuma.sk/zivot-s-reumou/pocity.html).

Children attend these Klub Kíbig camps with their parents, and sometimes with their siblings. But we consider this to be the most important contribution because rheumatic and musculoskeletal diseases (RMDs), and their consequences, are about the whole family and these meetings help relatives to overcome the fear of the future. Both adults and children with RMDs share their experiences and create unforgettable friendships for life.

And what message would we like to share with everyone?

"Our children are like other children. They can do everything that they expect of life. Let them try to fulfil their dreams, even the unrealistic ones. Everything is possible, they only have to be more careful and assess possible risks and dangerous situations. Nowadays these children are like their peers – they study abroad, fulfil their travelling and professional ambitions and parental dreams. Not everyone can be a scientist, a celebrity or an athlete. Nevertheless they can try to be as happy as anyone else." These words also confirm the long-term efforts of SLAR: **to include children with RMDs into society and to let them have a fulfilling life.**



# EULAR activities

## Social Media taken by storm High 5 for World Arthritis Day 2015!



2015 has been a very successful year for World Arthritis Day (WAD) and we would like to thank all of you as your support has been crucial! More than 1000 High 5 pictures were received, more than 130 events related to WAD were featured on our Events

Map, and social media was exceptionally active and spreading the word fast reaching new audiences inside and outside of Europe. Carefully chosen Instagram influencers helped to spread the message further and, through their campaign, reached 4.78 million people.

At national level, the campaign helped organisations to talk to important key stakeholders and agree mutual activities and goals. While WAD 2015 focused on raising awareness, for 2016 we will feature individual stories and highlight the reality of living with a rheumatic or musculoskeletal disease (RMD).

## World Arthritis Day 2016 'The Future in Your Hands'



'The future in your hands' campaign will ask people to share their stories as either

a picture or a video about how they have taken action to live their life to the fullest with a rheumatic or musculoskeletal disease (RMD), and helped to support others with RMDs.

By bringing personal stories to life, 'The future in your hands' campaign will provide greater insights for people with RMDs, their families and friends, healthcare professionals, carers, researchers, policy-makers and patient organisations, and also for the general public.

Your contribution will be essential for the success of the campaign. Soon we will share the new toolkit and instructions on how to participate in this activity – watch out on [www.worldarthritisday.org](http://www.worldarthritisday.org) and let's keep rolling for WAD 2016!



**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](http://www.eular.org)



Follow EULAR and World Arthritis Day on Facebook and Twitter

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EULAR supports the BJD: [www.boneandjointdecade.org](http://www.boneandjointdecade.org)