

# e - BREAKTHROUGH

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

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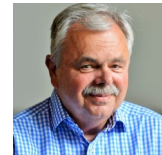
## Dates for your diary:

- **15-17 April:** 19th EULAR Annual European Conference of PARE, Sofia, Bulgaria  
**Watch live streaming:**  
[http://eular.org/pare\\_annual\\_conference.cfm](http://eular.org/pare_annual_conference.cfm)
- **2 May:** World Ankylosing Spondylitis Day
- **10 May:** World Lupus Day
- **12 May:** Fibromyalgia Day
- **20 May:** World Auto-Immune Arthritis Day
- **8-11 June:** EULAR Annual European 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)

## Great events ahead by Dieter Wiek, Chair of the EULAR Standing Committee of PARE



### Dear members of the PARE community and friends of PARE

We are looking forward to two great events in the first half of 2016. PARE's annual conference from 15 – 17 April in Sofia offers lots of fantastic workshops that will showcase best practices and give participants lots of opportunities to exchange ideas and experiences. In turn that will hopefully generate ideas for the work at home.

At the EULAR Annual European Congress of Rheumatology in London, PARE will present a great variety of sessions with high profile speakers. The activities of our member organisations and the voice of patients with rheumatic and musculoskeletal diseases (RMDs) will be represented through oral abstracts and in poster presentations that illustrate the encouraging work done by our member organisations. With your presence at

our PARE sessions, and at the Standing Committee Meeting of PARE, you will show your interest and strengthen the work of PARE and of EULAR.

Our World Arthritis Day 2016 campaign has started. This year's theme is *"The future in your hands"*. We are asking you to share your story about how you have taken action to live your life to the fullest or how people support others with RMDs. Just write your story and upload a picture or video that includes your hands. See the article on page 3 for further details. Let's make this a really global campaign.

I hope I can meet and talk to lots of you at the upcoming events.

Dieter Wiek



## EULAR Congress London 8-11 June 2016

Only a few weeks to go until 8–11 June when the attention of the whole world of rheumatology will focus on London. Scientists, health professionals and people with rheumatic and musculoskeletal diseases (RMDs), and their respective organisations, will gather for the EULAR Annual European Congress of Rheumatology to discuss

the latest advances in the field of RMDs through lectures, workshops, abstracts, poster presentations and symposia.

"The 2016 PARE programme at the Congress has many hot topics on its agenda – we will discuss how to optimize treatment and patient care, hear the latest news on pain, see what is done for rare diseases, and hear more about our key topic 'taking control and empowerment'. Our Stene Prize Award and the PARE Abstract Award will also feature in the Congress Opening Plenary Session" says Marios Kouloumas, EULAR Vice-President representing PARE.

The PARE Booth team in the EULAR Village also looks forward to welcoming delegates from all over the world, and to sharing the latest information and material about the projects and work of the Standing Committee of PARE.



## Introducing the EULAR Standing Committee on Clinical Affairs (ESCCA)

by Prof. Ronald van Vollenhoven\*

ESCCA is the EULAR Standing Committee of Clinical Affairs. Behind this slightly vague-sounding name are some of the most outwardly visible activities of EULAR, and it is therefore a great honour for me to be the current Chair of this Standing Committee. Many years ago ESCCA used to be called “ESCISIT” – the EULAR Standing Committee on interventional studies including clinical trials. But over the years, it became clear that more and more activities were deployed under this banner that were very important but did not quite fit the older name, and therefore the name was changed. Currently, the most important ESCCA activities revolve around the development of **EULAR criteria, EULAR recommendations and EULAR Points to Consider**, all for clinical topics including diagnosis and treatment. Until a few years ago ESCCA also funded clinical research projects (and some of these projects may still be running) but funding is now done through the Foundation for Research in Rheumatology (FOREUM) and this is no longer part of the ESCCA mission.

Today, ESCCA oversees a large portfolio of initiatives of the kinds mentioned above. These cover most of the inflammatory musculoskeletal diseases and systemic inflammatory ‘rheumatological’ diseases, as well as most of the major non-inflammatory musculoskeletal diseases. The long list of currently ongoing activities can be found on the [EULAR homepage](#) and, importantly, it includes second and third updates or recommendations, criteria etc. that are now underway in many instances, indicating maturity and stability of the process. For example, the EULAR recommendations for the treatment of rheumatoid arthritis are currently being revised (it is expected that they will be presented at the EULAR Congress in London), in order to remain consistent with the most recently published data and regulatory approvals.

The process for working under the auspices of ESCCA and EULAR has been clearly set out in the Standard Operating Procedure (SOP) as revised last year by the past-chair of ESCCA, Désirée van der Heijde. Any person who belongs to a EULAR-affiliated society or association can submit a proposal using a standard format. He or she is considered the ‘Convenor’ of the proposal and the proposal also must identify a methodologist. The proposal must describe why the work is necessary, how it will be done, and who are proposed as members of the task force. Usually the task force consists of around 20 individuals, and this must include at least two patient representatives, two EMEUNET members (younger rheumatologists or rheumatology fellows) and a health professional. The

process typically consists of a meeting of the task force, a systematic literature review, and a second meeting. Submitted proposals are screened by the ESCCA chair for consistency with the SOP and practical aspects, but it is the Executive Committee that decides whether the proposal receives the green light and is funded.

For the future of ESCCA I anticipate that there will be further maturation of existing directions, and also logical extensions of current areas. I hope that we will increasingly see collaborative projects between our organisation and other large international organisations. We are already working together in many areas with the American College of Rheumatology (ACR) and The Paediatric Rheumatology International Trials Organisation (PRINTO), but we could do more together with other Leagues of Rheumatology, disease-specific groups (for example The Assessment of SpondyloArthritis International Society (ASAS); the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA); the Systemic Lupus International Collaborating Clinics (SLICC), and other specialty societies or leagues.

I do think there is potential for improvement in some areas. As with all Standing Committees, each member society/association is allowed a representative in ESCCA. Delegates are properly identified, but their involvement in the activities is variable. It may also be necessary to increase the oversight related to the conduct of approved projects. Current EULAR operating procedures request annual updates on the ongoing projects, but this may not in all instances be sufficient, and long delays have occurred in some instances that might have been prevented with better oversight.

One particularly thorny issue relates to the lack of a mechanism for EULAR to adopt existing initiatives. It happens from time to time that a good and important initiative is started by a group outside EULAR, and there is currently no mechanism for EULAR to then become involved – even if the project is very good and ‘worthy’ of EULAR status. I have proposed to the EULAR Executive Committee to investigate whether such a mechanism should not be developed. Finally, there is no clearly articulated long-term “ESCCA Vision” at this time, and together with colleagues in ESCCA I hope to be able to achieve agreement on an appropriate formulation in this regard.

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The 2016 World Arthritis Day (WAD) campaign 'The Future In Your Hands' asks people to share their stories through a video or a picture showing how they have taken action to live their lives to the fullest.

Our aim is to educate people about the burden of rheumatic and musculoskeletal diseases (RMDs) by sharing the inspiring personal stories of those who do live their lives to the fullest.

## World Arthritis Day 2016

by EULAR Secretariat



We know you and your communities have wonderful stories to share, so we need your help to do this!

You can ask people to submit their stories in many different ways, including:

- Through our website [www.worldarthritisday.org](http://www.worldarthritisday.org)
- Via social media (YouTube, Twitter, Instagram and Facebook)

You can also help to spread the word for 'The Future in your Hands' campaign in many different ways, including:

- Sharing campaign information in newsletters
- Informing people at events about the campaign
- Sharing your own story as an example
- Offering to help others write their story

Taking part in 'The Future in your Hands' campaign as an individual or an organisation is easy: upload your story to the WAD website alongside the photo, or alternatively you can upload your story to Instagram with a short video of your hands using the hashtag #WADStory. You should also share this on all your social media channels using #WADStory so that everyone in your network sees it.

The cut-off date for submitting your story is 29 July 2016. After this date, you may still submit your story to the website but it will not have the opportunity to appear in the montage video of stories that will be published on 12 October.

For more information please see the [World Arthritis Day website](http://WorldArthritisDay.org).

## News from EULAR Young PARE by Petra Balážová



EULAR Young PARE Working Group members are actively working on fulfilling their objectives. We have just recently launched the Virtual Knowledge Centre – an online toolbox exclusively for the Young PARE network of liaison persons, representatives of European national organisations, so that they can share best practices, knowledge and experiences. It is a lively environment and we welcome feedback and constructive suggestions from liaison persons on what more to include. This tool can be found on our website [www.youngpare.org](http://www.youngpare.org).

One of our objectives is to have the perspective of young people included in all aspects of EULAR PARE initiatives. I have to say that we're successful in this particular area. One of the PARE task forces focuses on the organisation of the EULAR Annual European Conference of PARE that will be held in Sofia this year. The delegates will have the opportunity to take part in two youth workshops. One will be focused on setting up a youth group within an organisation. Participants will have the opportunity to listen to the story of how a successful youth group was set up in Italy. The second workshop will concentrate on "Facilitating transition in

*young people with rheumatic and musculoskeletal diseases (RMDs) from child to adult".* It will provide the delegates with a list of ideas/suggestions on how to support young people and their families when care roles change.

We are also going to have an informal meeting for young people on Sunday morning after the conference. We hope to see many of you there!



## Meeting of Chief Executive Officers of PARE organisations by EULAR Secretariat

On 4/5 February 2016 the Deutsche Rheuma-Liga (DRL) hosted the EULAR PARE CEO Exchange Meeting in Bonn, Germany.

The meeting gathered the leaders of those PARE organisations which have paid full-time CEO positions and employ at least five paid staff members. "This platform is extremely useful to us as we all face similar challenges. The small size of the group allows an intense exchange of information. It is also a safe environment to discuss sensitive issues and learn from our counterparts in Europe" said Ailsa Bosworth, CEO of the UK National Rheumatoid Arthritis Society (NRAS).



CEOs attending the successful exchange meeting hosted by the Deutsche Rheuma-Liga in Bonn

Ursula Faubel, CEO of the DRL, introduced the set-up of her organisation, which aims to welcome its 300,000<sup>th</sup> member in October. Children and youth work plays an important role in DRL and the organisation recently launched a new online platform dedicated to young

people with rheumatic and musculoskeletal diseases (RMDs) in the transition phase (<https://mein-rheuma-wird-erwachsen.de>). The DRL launched its first app "Rheuma-Auszeit" in January and aims to launch a newly developed exercise programme in 2016.

The agenda for the two half days also featured the hot topic of fundraising. To ensure a sustainable income flow is a key aim for many organisations. A survey organised by Arthritis Ireland confirmed that public awareness is still focused on cancer and cardiovascular diseases. RMDs are not perceived as being so serious or life threatening, and consequently public support is weak. John Church, CEO of Arthritis Ireland, presented the latest video that his organisation has developed, with the aim of making RMDs a worthwhile cause for support.

The CEOs were introduced to the EULAR PARE Agenda for 2016 by Dieter Wiek, Chair of the Standing Committee of PARE. They also learned about the latest developments at EU level from the EULAR EU Office in Brussels, and how their influence at national level can help to make a real difference for EULAR's EU related work.

## Engagement Programme: Finland by EULAR Secretariat

In November 2015, a EULAR delegation consisting of the EULAR Vice President representing PARE, Marios Kouloumas, the Chair of the Standing Committee of PARE, Dieter Wiek, PARE board member, Dora Papastavrou, and Florian Klett from the EULAR Secretariat visited the Finnish Rheumatism Association under the EULAR PARE Engagement Programme. The aim was to identify successful, transferable activities and concepts, to develop ideas for pan European initiatives and to share knowledge about EULAR.

Presentations by Miranna Seppälä-Saukkonen on "How does the Finnish Rheumatism Association lobby" and, by Sini Hirvonen, on "Youth and family activities" showed the breadth of activities and the expertise of the staff and volunteers in the Association. It has 159 local member associations with about 41,000 individual members. It also has an umbrella office for rare diseases, and several other disease specific organisations. The Finnish Association is part of SOSTE, the Federation for Social Affairs and Health (202 NGO members) and POTKA, the network of patient organisations (42 patient organisations with 500,000 members). Maria Ekroth, CEO Finnish Rheumatism Association commented "The exchange with EULAR PARE was very valuable and really important. Collaboration with PARE and national organisations is key; together we can reach our goals much *faster!*" The EULAR delegation engaged in several different discussions and activities. For example, a children and parents event, organised by tourism students and Association volunteers, and involving a national celebrity magician and dozens of workshops for children with juvenile idiopathic arthritis (JIA).

From Arto Satonanen, Member of Parliament, the delegation learnt that the Finnish health care system is under financial pressure. The EULAR Charter for Work was presented, and arguments that 'investing in prevention is key when redesigning the Finnish health care system to implement person centred-care' were given to counter budget cutting perspectives.

If you would like to know more, please visit read the [full report on the EULAR website](#) or contact [florian.klett@eular.org](mailto:florian.klett@eular.org)



At the Finnish Parliament (from left to right) Lea Salminen, Maria Ekroth, Anastasios Papastavrou, Marios Kouloumas, Dieter Wiek, Florian Klett, and Theodora Papastavrou



Liga Portuguesa  
Contra as Doenças Reumáticas

### How to change your organisation to user-led

by Elsa Mateus, President, LPCDR



January 2015 was a historic moment for the Portuguese League against Rheumatic Diseases (LPCDR). For the first time in 33 years of its existence, a patient became President of the Board. For the 2015-2018 term, LPCDR's governing bodies consist of eight patients, two rheumatologists and one health professional.

The knowledge and experience I have gained within EULAR/PARE allowed me to present a plan of action for LPCDR, providing credibility for the user-led principle, and facilitating the engagement of patients. Six of us have been variously involved in PARE activities. Like me, three of them had submitted essays to the national Edgar Stene Prize competition and two of them had attended the Annual European Conference of PARE. Participating in World Arthritis Day campaigns, or in Patient Research Partners training, was also a common factor. Experiencing the empowerment that PARE provides has really made a difference to our active participation in our organisation.

In a culture where most patients cultivate the *paternalistic* model of the doctor-patient relationship, having patients leading the organisation was unsettling. We had to prove our ability in governance, in public relations, and in political and social affairs. And in the case of LPCDR, we had to go beyond our own perspective and patient experience in order to develop empathy and advocacy for other rheumatic and musculoskeletal diseases (RMDs).

We were able to build a team where chronic pain, rheumatoid and juvenile arthritis, Sjögren's Syndrome, osteoarthritis, spondyloarthritis and Behçet Disease are represented in our governing bodies. This has also enabled us to start working closer with other patients organisations, joining efforts to empower patients, and to obtain more public visibility and credibility among stakeholders. Rheumatologist Dr. Augusto Faustino, the former President of the Board, is now the President of LPCDR's General Assembly and Prof. Helena Canhão, is one of the Vice-Presidents of the Board.

Together we are stronger. If you feel confident enough to assume the responsibility, you may be surprised to find that other patients are willing to support you and join your team. **Make your change happen!**



### Knowledge Transfer Programme The Netherlands/Poland/Romania

by Linda van Nieuwkoop, Chair, Youth-R-Well.com



**An online platform is a successful media system where peer-to-peer support and information sharing for young people with rheumatic and musculoskeletal diseases (RMDs) can take place.** In The Netherlands we already have such a platform for youth, called Youth-R-Well.com. Many countries that want to build a similar platform find it hard to initiate, build and maintain a successful platform. We wanted to support this process, so we wrote a guide for building an online platform for young people with RMDs.

In May 2015, a meeting took place in Amersfoort, The Netherlands, supported by the EULAR PARE Knowledge Transfer Programme (KTP). Using the new guide, we helped participants from the EULAR PARE national member organisations of Poland and Romania with the implementation of their youth platforms.

During our two day meeting we discussed several topics that are important when starting an online youth platform. The participants worked on their own plan for starting a youth platform in Poland and Romania. By sharing our experiences from Youth-R-Well.com, and showing examples of other online platforms, we tried

to inspire the participants on what could work in their own country.

This was the first KTP programme fully dedicated to young people with RMDs. For most young people involved in the KTP it was their first experience in an international meeting with other youth volunteers with RMDs. Apart from the programme, personal experiences were also shared and the participants learned more about cultural differences, and about the diversity of health care systems across Europe and how this might influence coping with the disease.

It was great to see how everyone was highly motivated and how this meeting also contributed to empowering young volunteers. I hope Poland and Romania will soon be able to develop their own online youth platform, and hopefully other countries will also benefit from the guide we wrote.



Participants from Youth-R-Well.com and Poland and Romania at the meeting in Amersfoort in May 2015



# Country news



## News from AGORA

by Souzi Makri, Chairperson



AGORA, a platform for people with rheumatic and musculoskeletal diseases (RMDs) in Southern Europe, has been active since 2011 engaging its members in raising awareness of RMDs .

In 2012, AGORA launched its “Partners in Treatment” project, aimed at empowering people, with early stage RMDs, in their communication with medical professionals. The project’s deliverables were the “Companion Guide for the Self Management of Rheumatoid Arthritis” and “Quick Reference Cards”, in English. In early 2015, AGORA translated these materials into the languages of its members. Please see: <http://agora-pait.com>

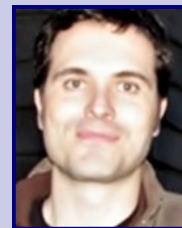
Between 25 – 27 September 2015, AGORA held its annual conference in Heraklion, Greece, entitled “Patients’ Rights to Better Health Care: Highlighting the different approaches for treating RMDs”. The conference was very successful and the participants had the opportunity to engage in very constructive discussions, as well as to participate in more practical workshops. Amongst the topics discussed were: the economics of rheumatoid arthritis; and the benefits of multidisciplinary care for people with RMDs, in combination with complementary non-pharmacological treatments.



Participants at the 2015 AGORA Annual Conference

More information about AGORA and its activities can be found on our website: [www.agora-platform.eu](http://www.agora-platform.eu)

## In Memory of Gonzalo Aldenueva



It was with great sadness that the Standing Committee of PARE received the news that our dear friend and colleague, Gonzalo Aldenueva, from Spain, had passed away in December 2015. Gonzalo was Chairman of the Management Board of the Spanish Behçet's Disease Association, a Board member of LIRE (Spanish League Against Rheumatism), and was elected to the PARE Board from 2014-2015. Gonzalo was full of enthusiasm and ideas. He believed in teamwork and one of his favourite quotes was “Together we are stronger”. He will be greatly missed and our thoughts are with his family and friends.

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, Twitter and Instagram

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

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