

## e - BREAKTHROUGH

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

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## Dates for your diary:

- **1 October–31 January 2017:** Abstract submissions for EULAR Congress 2017, Madrid
- **12 October:** World Arthritis Day
- **12 October:** EULAR Conference, Brussels
- **29 October:** World Psoriasis Day
- **3 December:** International Day of Persons with Disabilities
- **31 December:** Deadline for Knowledge Transfer Programme applications
- **31 December:** Deadline for Stene Prize 2017 essays to national EULAR member organisations of PARE
- **24-26 February 2017:** 20th EULAR Annual European Conference of PARE, Lisbon, Portugal

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)

## World Arthritis Day! by Dieter Wiek, Chair of the EULAR Standing Committee of PARE



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

Only a few months have passed since we enjoyed the fantastic EULAR Congress in London and we are already planning for the forthcoming EULAR Congress in Madrid 2017. Thanks to all of you who have sent in your ideas and comments for the programme. Your contributions are essential for a successful PARE programme.

I'd like to introduce the two new PARE Board members Polina Pchelnikova and Kristijonas Mazūras, who have rejuvenated the Board. I'd also like to welcome the new Chair-elect Nele Caeyers, well-known to many of you, and who has already supported PARE in many ways.

We are looking forward to two great events. On World Arthritis Day, 12 October, the EULAR Conference in Brussels will deal with the important topic "Reducing the

burden of chronic diseases in the workplace". Thank you for participating in our survey on "Health and Safety at Work". The results will be presented at this conference.

We are proud that so many of you took part in our World Arthritis Day campaign and sent fantastic entries. See below who will be featured in the montage video.

The EULAR Annual European Conference of PARE in Lisbon from 24-26 February 2017 will feature early diagnosis and self-management, and focus on how organisations can contribute to better healthcare. An exciting agenda ahead for all of us!

Hope to meet and talk to you in Lisbon and/or in Madrid 2017!

Dieter Wiek



Thank you for your great support for the World Arthritis Day campaign 'The Future In Your Hands'. We asked people to share their stories about how they have taken action to live their life to the fullest with a rheumatic and musculoskeletal disease (RMD).

Many people shared their stories on the [www.worldarthritisday.org](http://www.worldarthritisday.org) website, helping to make the impact of these diseases more visible, and better understood by both the wider RMD community and by the general public. Five of the stories submitted have now been included in a montage video. Choosing

the five stories was not an easy task as they were all inspirational and very touching! However the judging group selected the following:

**Lill Due, Norway (Ankylosing Spondylitis)**  
**Marija Kosanovic, Serbia (Juvenile Idiopathic Arthritis);**  
**Claudine Goyens, Belgium (Systemic Lupus Erythematosus);**  
**Ailsa Bosworth, United Kingdom (Rheumatoid Arthritis (RA));**  
**Theodora Seitaniidou, Greece (Juvenile RA)**

We would like to congratulate everyone who shared their story and contributed to this campaign. The montage video can be viewed on [www.worldarthritisday.org](http://www.worldarthritisday.org) It can also be downloaded and shared on your organisation's website or via social media. Don't forget to include it in your World Arthritis Day activities.

## News from the PARE Board

by EULAR Secretariat



The PARE Board meeting in Zurich in September 2016 (left to right) Nele Caeyers, Kristijonas Mazūras, Elsa Mateus, Polina Pchelnikova, Marios Kouloumas, Dieter Wiek, Petra Balážová, Dora Papastavrou, Boryana Boteva

The PARE Board, led by Chair Dieter Wiek, held its annual meeting on 3-4 September 2016 in Zurich, Switzerland. The Board currently has 9 members: Petra Balážová (Slovakia) representing Young PARE, Boryana Boteva (Bulgaria), Nele Caeyers (Belgium), who is the Chair elect, Marios Kouloumas (Cyprus) EULAR Vice President, representing PARE, Elsa Mateus (Portugal), Dora Papastavrou (Greece), and two new members (see opposite).

The PARE Board had a full agenda, starting with a review of the PARE Board's role and composition. The current role of the PARE Board as a 'Think Tank' and a body to monitor and oversee PARE-related projects and activities was reconfirmed. Important discussions took place on how future members could best be prepared for a meaningful role on the PARE Board. Suggestions now include a mandatory involvement in PARE projects for at least 2 years. "When I started my work on the PARE Board I felt overwhelmed by all the new information. Although I have always followed the work of PARE quite closely there are so many activities taking place, and EULAR is a very complex organisation." said Nele Caeyers. She added "Now, after some time, I feel more relaxed and ready to take on some responsibility. I think it will be useful for all involved if new PARE Board members have the chance to grow gradually into the work and join with a certain

degree of knowledge. It is great that I can be involved in shaping the future now as any changes will be implemented during my term of office as Chair." Details of the future set up are currently being finalised and will be presented to the Standing Committee by end of 2016.

The Board also discussed various project-related strategic decisions, including the EULAR Strategy that will need to be reviewed in 2017, and considered new objectives. The PARE Board will meet again after the EULAR Annual European Conference of PARE in Lisbon on 26 February 2017.

### Welcome the new PARE Board members



#### Polina Pchelnikova (Russia)

For the last 6 years I have been involved in the work of our Russian patient organisation "Nadezhda", starting as a regular member and now being the leader of the Moscow branch. My work in healthcare and my professional life require good communication skills, ability to operate strategically and working in international teams as well as strong leadership skills and responsibility - skills that can help the PARE Board reach its objectives.

#### Kristijonas Mazūras (Lithuania)

Board member of the Lithuanian Arthritis Association. I am ready to deliver my organisational and strategic skills as well as apply my knowledge as an IT professional to the advantage of EULAR PARE. My working experience of more than 20 years combines activities in international relations with teamwork and management abilities. I am eager and look forward to using my knowhow and experiences to benefit the range of working areas within the Board.

## EULAR Congress 2017 Madrid: Abstracts and bursaries



**Are you ready?** From 1 October 2016 to 31 January 2017 the EULAR abstract system for the EULAR Congress 2017 in Madrid is open and ready to receive your contributions! Your contributions are crucial in making the PARE programme relevant and interesting for your fellow delegates. We count on you to share your campaigns, projects and expertise! Remember too that poster presenters are now offered much deserved attention through our official PARE Poster Tours. If you would also like to apply for a bursary please note that this is a separate application process which needs to be completed at the same time as submitting your abstract. If you have any questions about abstracts or bursaries please contact Birte Gluesing at the EULAR Secretariat at [birte.gluesing@eular.org](mailto:birte.gluesing@eular.org)



## Introducing the EULAR Standing Committee of Epidemiology and Health Services Research (ESCEHSR) by Axel Finckh\*

This standing committee covers two distinct areas: **Epidemiology and Health Services Research**. One of the main aims of the standing committee is to support and to facilitate research in these fields, which have been traditionally among the topics receiving most abstracts for the EULAR Congresses. Epidemiology covers the study of the causes of disease (e.g. risk factors) and their effects on health in specific populations. A better understanding of what produces the development of specific diseases, hopefully then translates into preventive measures and policy decisions, which is part of what is covered by the other component of this standing committee namely the Health Services Research study group.

Another aim of the ESCEHSR standing committee is to equip and train young researchers in epidemiological methods both for population and clinical based studies and to foster collaborative studies between member countries. A good example of this is the “Registers and Observational Drug Studies” (RODS) – a study group, which organizes a biennial meeting and has performed collaborative analyses of a number of European drug registers looking at rarer outcomes, such as melanoma. Specific courses are provided in collaboration with the EULAR standing committee of education (ESCET), such as the EULAR Epidemiology Course or the EULAR Course on Health Economics in Rheumatology. Another good example of ESCEHSR efforts to facilitate research is the ‘Outcomes Measures Library’ (<http://oml.eular.org>), which contains documentation on validated questionnaires in the different languages, which may be used for clinical research projects.

Finally, the standing committee strives to support EULAR’s EU public affairs group by providing statistics and figures that may be used to lobby for better recognition of rheumatic and musculoskeletal diseases (RMDs) by policy makers and politicians. Recent evidence provided by Health Services Research (the Eumusc.net project, the Global Burden of Disease Study) revealed that RMDs are the first cause of disability in Europe, accounting for about one third of all disabled people. Thanks to public affairs activities, the importance of RMDs is being better appreciated and have now been recognized as one of the major chronic diseases both by the EU and the WHO. We hope that this will translate in the years to come into better support of specific health care services and more funding expressly dedicated for research in RMDs.

All Standing Committees meet at least once a year and each member society is allowed a representative in ESCEHSR. The study groups, within the standing committees, may have more frequent contacts and more intensive collaborations. Starting next year, each of the study groups will present itself in front of a poster during the annual EULAR congress. We hope this will facilitate the involvement of the different stakeholders, including patients. Don’t hesitate to come and visit some of the ESCEHSR study group representatives!

\*Prof. Axel Finckh, Division of Rheumatology  
Geneva University

## 20th EULAR Annual European Conference of PARE, Lisbon by EULAR Secretariat



The 2017 EULAR Annual European Conference of PARE will be held from 24 – 26 February in Lisbon, hosted by LPCDR (LIGA PORTUGUESA CONTRA AS DOENÇAS REUMÁTICAS), the Portuguese League Against Rheumatic Diseases. And the PARE Conference will celebrate its 20<sup>th</sup> anniversary! More than 120 delegates are expected to join this established and important event in the EULAR calendar. For the first time, a limited number of organisations from outside Europe are invited to participate. “It is important for EULAR to engage with patient organisations worldwide to look for synergies, and to exchange knowledge in areas which are important to all of us” said Marios Kouloumas, Vice President of EULAR, representing PARE. The topic of

this year’s conference will highlight EULAR’s focus for the coming year – **“Don’t delay, connect today. Working together towards early prevention, diagnosis and access to care in rheumatic and musculoskeletal diseases”**. “This is also a very hot topic for Portugal and I am really delighted that the Conference will help us to emphasize its importance with our key stakeholders. We are grateful for the support of EULAR and would like to thank in particular Prof. Gerd-Rüdiger Burmester, President of EULAR, who will not only open the Conference on behalf of EULAR and give the key-note talk but who will also join us for a round-table discussion with our politicians in the Portuguese Parliament” said Elsa Mateus, President of LPCDR.

# Introducing ANMAR Young and ENCA



## Gruppo ANMAR Young: growing together!

by Silvia Ostuzzi, EULAR Young PARE Liaison Person, Italy

ANMAR's (Italian Rheumatism Association) *Step Zero* meeting on 20-22 November 2015 in Milan, the first Italian meeting for young people with rheumatic and musculoskeletal diseases (RMDs), marked the beginning of the *Step Zero* Project.

The meeting involved 12 young patients aged 18 to 35 from 8 different Italian regions. Our guest speakers were Linda van Nieuwkoop and Wendy Olsder from Youth-R-Well.com (our partner association in the Netherlands), Silvia Ostuzzi, ANMAR (EULAR Young PARE Liaison Person, Italy) and Sara Severoni (representative of ANMAR's board). The project was made possible through the support of EULAR's Knowledge Transfer Programme.

The aim of ANMAR's *Step Zero* Project is to open up and share experiences between young people in Italy living with an RMD. The Milan *Step Zero* meeting brought young people together for the first time and the 'ice-breaker' format was highly motivating and inspiring, leading to the creation of our newly born Italian youth group: Gruppo ANMAR Young!



Participants at ANMAR's *Step Zero* meeting in Milan in November 2015.

Now transitioning from *Step Zero* to *Step One*, we are growing stronger together, wishing to involve more and more young people. Since our November meeting, a closed page on Facebook has been set up to make our work easier and truly shared. We also have an open Facebook page, currently reaching more than 300 contacts. We are planning a youth event for World Arthritis Day 2016 in Rome. In addition, we have just

launched an online storytelling campaign '*Keep calm and tell me your story!*' encouraging Italian young people with RMDs to open up and raise awareness about their unmet needs. The whole group is contributing to this project: a booklet containing all the stories collected through the campaign will be printed and distributed, together with our brand new t-shirts and our colourful logo and motto, which just states very proudly and loudly that **#wecare!**



## European Network for Children with Arthritis (ENCA)

by Wendy Costello, ENCA Chairperson



2015 ENCA Conference in Rome

ENCA is a group of Juvenile Idiopathic Arthritis (JIA) associations from across Europe working together to establish best practice, to learn from one another and to promote common projects. ENCA was established in 2002 and this current committee has been in place for one year. The committee members, all working on a voluntary basis, are Wendy Costello, Yona Egert, Mirjam Kopic, Anita van de Louw and Anton Gruss. The committee meets face to face once a year with regular Skype meetings the rest of the year. We have a close relationship with the Paediatric Rheumatology European Society (PRES), EULAR, PARE and particularly Young PARE.

ENCA took an active role in the European SHARE (Single Hub and Access point for paediatric Rheumatology in Europe) project together with PRES and worked hand-in-hand with Dr Bas Vastert and Professor Nico Wulfraat. We had a presence at the 2016 EULAR Annual European Congress of Rheumatology in London and have participated in various conferences. We have also worked with PRINTO (Paediatric Rheumatology International Trials Organisation) on their website for family associations. ENCA is committed to supporting countries that need help to establish associations.

We are looking forward to our conference on 29-30 September 2016 in Genoa, Italy. There is a packed programme with some very exciting speakers. We are very committed to the future of ENCA and our committee looks forward to a very exciting future. For more information see: [www.enca.org](http://www.enca.org)



## Volleyball tournament in The Netherlands

by Leen Salij, President, Stichting Bechterew in Beweging

For more than 10 years the Dutch Ankylosing Spondylitis (AS) patient organisation *Stichting Bechterew in Beweging (AS in Motion Foundation)* has organised events to promote physical activity for its members, including an annual volleyball tournament. E-Breakthrough spoke with the founder and president of the organisation Leen Salij (62) who has been a role model for many people who are confronted with the impact of AS.

### How did you get involved in the work for people with AS?

*Leen:* "I have lived with AS for over 40 years so I well understood the importance of trying to stay active with an illness like this. I thought that meeting to exercise in a local AS group should be fun. I also felt that there could be much to be learnt by linking with other AS groups in The Netherlands. That was the reason why I organised the first national volleyball tournament, inviting all local AS exercise groups to participate. Here we discovered the enthusiasm of the participants. We also saw how this sport could be used to demonstrate how important exercise is for people with AS. The success of the tournament encouraged us to continue our activities and so we then established the legal entity '*Stichting Bechterew in Beweging (SbiB)*'. Our board comprises six members and is supported by a medical advisory board of several rheumatologists. We also rely on the help of a large group of volunteers and we have a website ([www.stichting-bechterew.nl](http://www.stichting-bechterew.nl)) that gives people with AS the opportunity to put questions to an expert-by-experience because we consider that patient education is no less important than organising sporting events.

### What makes your organisation such a great success?

*Leen:* Over the past 11 years, the volleyball tournament has grown into a big one-day event in Utrecht where we have 8 playing fields with over 400 participants. Now the teams come from the Netherlands, Germany, Czech Republic and Bulgaria. In future, we hope to make it a real international event with teams also coming from, for instance, Denmark, Austria, Switzerland and Belgium.

A major reason for our success is the co-operation of our fantastic ambassador Annamarie Thomas (former skating world champion). She was diagnosed with AS which forced her to stop her sporting career. When I met her for the first time, I was impressed by her enthusiasm and saw immediately that she could inspire other people with AS. She immediately agreed and she has been an important supporter for the continuity and success of our events. I would call her the 'PR-pearl' of our organisation. It is wonderful to see how her active lifestyle and positive attitude inspires other people. In this way we think we



2016 Volleyball Tournament in Utrecht

make the best use of her popularity for the benefit of the people that we want to serve.

### Are there other reasons for success?

*Leen:* We are also grateful for the great interest shown by our sponsors. They see that we work hard and that we can reach a large number of patients with AS. Many pharmaceutical companies are interested in attending our events and in supporting our patient education initiative. This year we signed an agreement for collaboration with the Dutch Arthritis Foundation (Reumafonds) of which we are very proud. We hope that this will be the start of a long-term relationship.

### What are your future priorities?

*Leen:* Our mission is to promote physical exercise activities and self-management for people with AS. One of the priorities is to raise awareness of the importance of early diagnosis among general practitioners. At the same time we have developed a new website ([www.jongenrugpijn.nl](http://www.jongenrugpijn.nl)) for young people with low-back pain. By targeting both groups in our campaign, we hope to be more effective in reaching this difficult to find group. An advantage of the website is that it encourages people with AS to exchange personal experiences and knowledge.

### What is the Bechterew monitor?

*Leen:* We want to help people who are already diagnosed with AS. For them we launched a separate website called the [www.bechterewmonitor.nl](http://www.bechterewmonitor.nl). Here the patient can fill in two validated questionnaires (BASDAI and BASFI) to monitor their own disease process. The answers are translated into a personal diagram where people can follow over time how they are doing. This monitor also stimulates the use of different forms of social media by people with AS. At fairs and educational events in hospitals, we present the monitor and encourage hospitals to organise more physical activities for their patients.

### What is the date of the next Volleyball Tournament?

*Leen:* The next Tournament will be on **1 April 2017**.

# News from Brussels



## News from the European arena

by Neil Betteridge, Liaison Officer, Public Affairs, EULAR  
in conjunction with the EULAR Brussels Office



This has of course been a tumultuous period politically, but it does not have to hinder our progress. So EULAR remains focused on key policy developments e.g. the implementation of the Horizon 2020 Research Framework Programme, access to healthcare (including cross-border care) and renewed EU initiatives on chronic diseases. Particularly important for EULAR is new EU legislation on health and safety at work and we are supporting the EU Agency for Safety and Health at Work (EU-OSHA) "Healthier workplaces for all ages" campaign ([www.healthier-workplaces.eu/en](http://www.healthier-workplaces.eu/en)). Rheumatic and musculoskeletal diseases (RMDs) represent the largest group of occupational diseases (38%) and the main cause of work loss, absenteeism and early retirement. It is vital therefore that the views of EULAR and the whole RMD community are heard in the development of new legislation and policies. Please raise your voice and help us to do this on behalf of the RMD community.

Two events organised by EULAR in Brussels focus on these issues:

**Meeting of European Parliament Interest Group on RMDs, June 2016:** chaired by Roberta Metsola and Takis Hadjigeorgiou (Members of the European Parliament), this meeting looked at the likely impact of new EU legislation on RMD prevention. Former PARE Board member Alison Kent and I represented EULAR, Alison speaking alongside high-level representatives from the three main EU institutions. It was pleasing to hear the WHO representative say that RMDs was "no longer considered a Cinderella condition". Progress! There was agreement that action is required in order to prevent RMDs in the workplace and to improve job retention.

**The EULAR Brussels Conference 2016, which happens this year on the same day as World Arthritis Day:** this annual EULAR event is this time looking at "Reducing the burden of chronic diseases in the workplace. New policies for better working conditions and the retention of ill people at work". The aim of the event is to formulate policy recommendations to EU and national policymakers for the development of legislation and policies that better prevent RMDs in the workplace. It will also look at practical means to facilitate job retention. I hope you or a colleague can join us. For more information, visit the Public Affairs section of the EULAR website: [www.eular.org](http://www.eular.org)

**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)