

## e - BREAKTHROUGH

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

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## Dates for your diary:

- **10 May 2014:** World Lupus Day
- **20 May:** World Auto-immune Arthritis Day
- **11-14 June:** EULAR Annual European Congress of Rheumatology, Paris
- **18 July:** Deadline for WAD Vision 2043 entries
- **12 October:** World Arthritis Day
- **7-9 November:** EULAR Annual European Conference of PARE, Zagreb, Croatia

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)

## Building on a firm foundation

by Diana Skingle,  
Chairperson of the EULAR Standing Committee of PARE



### Dear Colleagues

Firstly I should like to thank those of you who have kindly sent messages of support on my new appointment. It is a very sad moment to be taking on this role. But I hope to be able to build on the very firm foundation that David Magnusson and his predecessors have put in place to guide PARE's activities.

2014 has some exciting possibilities ahead. In this issue you will read about the Patient Research Partners project that is becoming more and more important as researchers increasingly incorporate the views of patients into their projects. There are inspiring stories too from Cyprus, Hungary and Switzerland.

The Edgar Stene Prize Competition has again attracted some brilliant entries - the winner will be awarded the prize at the EULAR Congress. There is still time for you to enter the World Arthritis Day Vision 2043 Competition. We have extended the deadline until 18 July 2014 in order to capture all your solutions to some of the problems facing those of us living with RMDs. I would urge you to take part. We hope to carry your best ideas to influential stakeholders.

I very much look forward to seeing old friends and to meeting new ones in June at the EULAR Congress in Paris.



**The World Arthritis Day competition runs until Friday 18 July 2014.** Grab your chance to help to change the future for people with rheumatic and musculoskeletal diseases (RMDs) by entering the 'Vision 2043' competition. You could win a cash prize.

There will be two winners:

1. The European entry (from a EULAR member country) which has received the most online votes
2. The Global entry which has received the most number of online votes

Winners will each receive Euros 300. 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). Anyone can vote so make sure you tell your family and friends about your entry! See [www.worldarthritisday.org/vision2043](http://www.worldarthritisday.org/vision2043)

**Remember the deadline: 18 July 2014**

## Introducing Diana Skingle, new Chairperson of the Standing Committee of PARE



HE Ms Diana Skingle,  
British High  
Commissioner  
to the Republic of  
Seychelles  
(2004-2007)

Diana Skingle is a retired British diplomat. As a member of Her Majesty's Diplomatic Service she served in a variety of countries including Belgium, Morocco, Ethiopia and Seychelles. She developed rheumatoid arthritis (RA) in 2005. In conversation with the EULAR Secretariat, Diana spoke about her experience of developing RA:

*"In common with many people, I experienced the confusion and fear for the future that accompanies such a sudden and unexpected diagnosis. The realisation that there is no cure for RA was life-changing for me. The implications for family, career and lifestyle were uncertain. I relied heavily on information and advice from the United Kingdom's National Rheumatoid Arthritis Society (NRAS) to learn about the condition and to manage my expectations. Reviewing and re-organising my day-to-day activities gave me a new perspective and helped me to address some of the many challenges faced everyday by those of us with a chronic condition. Meeting other people with RA, and attending a self-management course, were the keys to seeing a way forward. But of course none of us can do it alone. The support of family, friends, and our healthcare team, is vital in helping us to find a way through."*

*I am now a volunteer and Trustee/Director of NRAS, and a keen supporter of the aims of organisations that seek to educate and support people living with rheumatic and musculoskeletal diseases (RMDs). I am also a patient research partner in the EUROTEAM project and a member of the Steering Committee of the Arthritis Research UK Clinical Study Group for Adult Inflammatory Arthritis. In 2011, I was delighted to be successfully nominated as a member of the PARE Board. I have been involved in many of its activities and I am now editor and designer of this e-Breakthrough magazine. PARE has a tremendous reputation. During my term as Chair of the Standing Committee of PARE therefore I hope to continue to make progress at national and international level to improve the lives of people living with RMDs across Europe. Working together makes us all stronger. We have the potential to achieve even greater things."*

## The Standing Committee of Paediatric Rheumatology

by Prof. Alberto Martini, Chairperson of the Standing Committee



**EULAR Standing Committees are set up to manage and perform the various activities of EULAR on behalf of the Executive Committee. Currently, eight Standing Committees are in place, covering the major areas of activity of EULAR. They provide a forum for specialists from all the European countries to meet and work together on specific projects.**

The mission of the **Paediatric Rheumatology Standing Committee of EULAR** is to improve the care of children with rheumatic 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 ten separate modules and will be available later this year. Totally run through the web it is designed to last for 9 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 transition from childhood to adulthood for those patients with a paediatric rheumatic disease in whom the disease persists into adult age.

*Prof. Martini is President of the Paediatric Rheumatology European Society (PReS) and Professor of Paediatrics at the University of Genoa and Director of Pediatria II Reumatologia (EULAR Centre of Excellence in Rheumatology 2008-13), G Gaslini Institute, Genoa, Italy.*



## Why use the term “Rheumatic and Musculoskeletal Diseases”?

by Neil Betteridge, International Liaison Officer, Public Affairs, EULAR

**Why has EULAR chosen ‘Rheumatic and Musculoskeletal Diseases (RMDs)’ as its favoured term to describe the conditions relevant to the organisation?**

The debate over the best way to use language inclusive of all the 200 or so conditions belonging to our field is not only longstanding but also, in the view of EULAR, unhelpful to our work. The variety of words and phrases used, plus the complexity of many of the words, often leaves the general public confused. We know that public awareness of RMDs is low, and that this is a problem. We also all hear sometimes from policymakers and the media that it is difficult for them to promote our cause when they are left feeling uncertain as to what diseases we are referring to when they try to understand the difference between ‘arthritis’, ‘rheumatism’, ‘musculoskeletal disorders’ and so on.

EULAR therefore decided it should develop a term with the greatest consensus amongst its stakeholders and then use it consistently.

To arrive at such a formula, some familiar arguments were voiced:

- The ‘Disease’ versus ‘Disorder’ debate was quickly settled. It was felt that every condition could be called a disease, which also bestowed greater seriousness and impact with the general public; ‘Disorder’ did not seem to recognise the way in which, for example, certain forms of

inflammatory arthritis were experienced. So ‘Disease’ was selected.

- ‘Arthritis’ is the word most commonly understood by the general public ... but it is non-specific and also connotes diseases of older people.
- ‘Rheumatic’ is specific and broad ... but those working in back pain and other musculoskeletal conditions do not see themselves as included within it.
- ‘Musculoskeletal’ is well understood by policymakers ... but not the general public – and does not necessarily include certain systemic conditions.

As neither ‘Rheumatic’ nor ‘Musculoskeletal’ were acceptable as ‘stand alone’ terms, they were combined. The final formula chosen, therefore, was ‘Rheumatic and Musculoskeletal Diseases’, and it has been used consistently by EULAR for the last 3 years.

It is also worth noting that following successful EULAR public affairs activity in Brussels, we have seen RMDs included into the text of the next research framework programme, Horizon 2020, using this terminology. This unofficial adoption of the term at European Union level is another strong argument in favour of it being widely adopted by all national societies, including organisations of People with Arthritis/Rheumatism in Europe (PARE).

## Paris is calling by EULAR Secretariat



Only 2 months to go until the doors of the EULAR Annual European Congress of Rheumatology open again – this year in beautiful Paris! There will be a comprehensive PARE programme with impressive speakers sharing their views and experiences, poster tours and plenty of opportunities for networking and sharing experiences and knowledge with colleagues from all over the world.

Please do join us for our pre-conference session on Wednesday 11 June (13.30 -14.30) to get a flavour of the exciting days ahead and useful information on finding your way around the Congress! We hope that all delegates will seize the opportunity to participate fully, be inspired and go home buzzing with new ideas to share! À bientôt!



## EULAR Dissemination Project

by Maarten de Wit, Project Convenor

**Patients organisations can improve the quality of health care services by making the health system more transparent. One way to do this is to inform and educate their members about existing treatment recommendations for rheumatic diseases.** These recommendations or guidelines often contain criteria for high quality care that should be followed by health professionals, but many patients are not aware of them. For this reason PARE has initiated a new project to develop a practical guide for national patient organisations. The guide should help them to disseminate EULAR treatment recommendations among patients. The project is coordinated by Dr Karen Schipper working for the VU University in Amsterdam.

In November 2013 the PARE task force for developing the guide met in Amsterdam to discuss the results of a systematic literature review about disseminating guidelines among patients. This review showed that there is not much evidence about effective

dissemination strategies. As a start, the task force, consisting of 6 patient representatives, 6 health professionals and 1 dissemination expert, agreed on a number of important conditions for dissemination: First, patients should be involved in the development of recommendations as early as possible. Second, a patient version of the original, scientific guidelines is necessary to make them understandable for patients. Third, every national patient organisation should review the recommendations and translate and adjust the patient version to their own culture and health system. Finally, everybody agreed that a printed patient version of the guidelines would not be sufficient. Effective dissemination needs a multi-faceted approach using a diversity of strategies and tools, including the use of the internet and social media.

The task force will now continue its work to develop more detailed recommendations for dissemination that will form the basis of the practical PARE guide.



## Patient Research Partners

by Nele Caeyers, Project Co-ordinator

### The Network of Patient Research Partners keeps growing!

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. A first group of patient research partners was trained in 2010, and all fifteen participants of this Network were closely involved in several projects throughout Europe.

Soon it was clear though, that the collaboration between patients and researchers was not always a success. Both parties needed guidance on how to optimize 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'.



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 details 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 fifteen trained patients. They are currently waiting to be given their first assignments.



*Group photo of the second group of Patient Research Partners, trained in November 2013 in Brussels, Belgium*

As the project has been finalized now, 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](mailto:Florian.Klett@eular.org)



Magyar Reumabetegek Egyesülete

## Hungary: Guinness World Record!

by Judit Ortutay, President of the Hungarian League of Patients with Rheumatic Diseases



In 2013, the Hungarian League of Patients with Rheumatic Diseases carried out the 'Take a paintbrush!' campaign. The aim was to raise awareness about rheumatoid arthritis (RA) and to help people with the disease get closer to each other and to their health care providers by using the tools of graphic art.

Painting *the world's biggest panoramic postcard*

together in eight cities of Hungary resulted in a positive teamwork experience for all participants: people with RA, doctors, nurses, family members, friends and media stars. Outlines of a painting made by artist and illustrator Aniko Roth were enlarged, printed on paper, and cut into 16 pieces. In each city, 2 sections were coloured by us. Two well known actors and two pop singers joined our campaign, which was followed throughout by the media. Each local programme started with a panel discussion about the burden of the disease, moderated by a professional reporter, and followed by the painting.

The result was a huge, 86.4 m<sup>2</sup> painting, which was the template for the world's largest panoramic postcard, completed by 12 October, World Arthritis Day. And it became an official Guinness World Record! It was a gorgeous feeling, and we all were touched deeply looking at the huge painting knowing that it had been painted with painful hands, mostly deformed by arthritis. The generous sponsor of this campaign was Pfizer Inc. We would like to thank every one who took part in this wonderful project.



Left to right: Mrs Gáborné Pethő, leader of association for arthritis patients "Move for Life", Dr Judit Ortutay, leader of the Hungarian League, Mr Csaba Bíró, RA patient, Mr Jack Brockbank, official judge of Guinness World Records



## Safe in everyday life by Monika Siber, Communications Manager, Swiss League Against Rheumatism



Rheumaliga Schweiz  
Ligue suisse contre le rhumatisme  
Liga svizzera contro il reumatismo

**Falls are the most common type of accident in people over 65. In Switzerland, they generate annual costs of 1.4 billion Swiss francs. For those affected, however, a fall has much greater consequences than merely a hole in the household budget.**

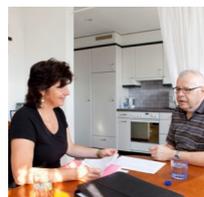
Together with partners from the health sector, the Swiss League Against Rheumatism has developed a prevention programme that intervenes precisely where, according to statistics, most accidents occur: in the person's own home. Common trip hazards include, for example, open slippers, loose carpeting and cables or objects lying around.

Specially-trained physiotherapists visit patients in their flat or house. In an initial step, the therapist determines the subjective assessment of the elderly person's risk of falling using a questionnaire. With the help of the answers, he/she compiles priorities for the subsequent objective assessment.

In a second step, he/she carries out specific tests that provide information on the effective risk of falling. One of these tests, for example, is the so-called "Five chair rising" test, in which the person rises from a chair and returns to a seated position five times within 15 seconds, without using the arm rests. During a walk

through the rooms, the therapist searches specifically for trip hazards and provides recommendations. Where possible, he/she implements the discussed measure immediately, for example by securing carpeting or identifying danger areas.

In the last part of the house visit, the elderly person receives an exercise plan that is adapted to his/her individual requirements. The physiotherapist determines a suitable performance location and provides the corresponding instructions. A follow-up check by telephone takes place four weeks after the initial house visit. If possible, the therapist visits the patients again 6 months later and conclusively documents the progress.



Personal advice  
within your own home

The project has been tested in a pilot phase in the canton of Lucerne. In 2013, around 100 house visits were carried out. Due to the positive feedback from the partners involved and the elderly people, the Swiss League Against Rheumatism is working on the introduction of this service across the country.

Further information: Swiss League Against Rheumatism, [www.rheumaliga.ch](http://www.rheumaliga.ch) email: [info@rheumaliga.ch](mailto:info@rheumaliga.ch)

# Country news



## Cyprus Health Professionals

by Costas Ioulianos, President of Cosmos Rheuma+



Health Professionals of Cosmos Rheuma+ after completing the volunteer action in Troodos villages; a rewarding experience

**Cosmos Rheuma+ was founded in December 2012, with the aim of promoting the co-operation between health professionals for the benefit of patients with rheumatic and musculoskeletal diseases (RMDs). Our members are physiotherapists, podologists, nurses, psychologists, nutritionists, social workers and sociologists.**

In September 2013, as a pilot trial, members of our society, gathered together and organised a trip to Kalopanagiotis, a village in the mountain range of Troodos, where the inhabitants are mostly elderly people with limited access to health professionals. The goal of the trip was to inform the villagers about the society and also to educate them on the importance of health promotion. All the people who visited the function were assessed and treated by the health professionals who took part in the event voluntarily.

Another successful event was organized on 25 January 2014, with the collaboration of various health professionals, members of our organisation—including rheumatologists, internal medicine doctors, GPs and pharmacists. The event took place in Dora, another remote village in the mountains of Cyprus. During the first event, 98 people were examined and during the second 150.

As these events were very successful, the Executive Board has decided to carry out two more events within the first six months of 2014. Our main goal is to visit remote villages and treat as many people as possible, especially the elderly and those who are not able to access health care easily.

The local community embraced this initiative and thanked us for our contribution. It was a rewarding experience for all our members; hopefully even more such events will be organized soon.

Health Professionals examining people with RMDs during the visits



**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)



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### EULAR Secretariat

Birte Glüsing and Florian Klett  
Seestrasse 240, 8802 Kilchberg, Switzerland

Tel: +49 (0)228 9621283 and  
+41 (0) 44 716 3035

Fax: +41 (0) 44 716 3039

Email: [Birte.Gluesing@eular.org](mailto:Birte.Gluesing@eular.org) and  
[Florian.Klett@eular.org](mailto:Florian.Klett@eular.org)

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

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Marios Kouloumas

#### PARE Standing Committee

##### Chairperson

Diana Skingle

#### EULAR Executive Secretariat

Birte Glüsing

Florian Klett

#### EULAR EU Office Brussels

Sören Haar

Federico Torres

#### Newsletter Editor and Co-ordinator

Diana Skingle

#### Publisher

EULAR Standing Committee of  
People with Arthritis/Rheumatism in  
Europe

#### Editorial Board

Maria Batziou

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Ingrid Pöldemaa

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)