

## 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 2013:** Abstract submission for EULAR Congress 2013 in Madrid
- **12 October:** World Arthritis Day
- **12 - 20 October:** Bone and Joint National Action Week
- **2 - 4 November:** EULAR Autumn Conference for PARE in Zurich, Switzerland
- **29 November - 2 December:** Bone & Joint Decade World Network Conference 2012, Ho Chi Minh City, Vietnam
- **31 December:** Deadline for submission of Stene Prize 2013 essays to national EULAR member organisations of PARE
- **31 December:** Deadline for 2013 Knowledge Transfer applications

## Message from the Chair of the EULAR Standing Committee of PARE

by Maria Batziou

Dear colleagues,

I am very pleased to introduce the first issue of the EULAR PARE e-newsletter. The need to enhance communication within the EULAR network and with external stakeholders by using the new electronic tools has been obvious for some time. These e-newsletters will therefore be published 3 times a year and will contain important news about the Standing Committee's work.

Our main aim is to update readers about our activities and projects at national and European level and to stimulate everyone to be actively involved. It will also serve as a platform for our EULAR PARE member organisations to present their own work and activities. The e-newsletter will also be a source of timely information about wider developments in the European arena.

In this issue you can read about World Arthritis Day (WAD) "Move To Improve" and our successful waving campaign, a statement from our new Board member Ingrid Pöldemaa, updates on our



exciting EULAR Autumn Conference for PARE in Zurich, WAD activities from our members in Denmark, Cyprus and Poland, a report on a recent country visit to Bulgaria, and developments related to EULAR's EU activities.

This e-newsletter will be sent to EULAR PARE member organisations and other EULAR key stakeholders with the hope that they will distribute it as widely as possible in their own networks.

Without the editorial team, the articles and their writers, this newsletter wouldn't exist. I would like to thank all those who contributed and made it possible.

I hope you all enjoy the e-newsletter. I very much welcome your feedback and contributions for our future issues.

## World Arthritis Day 2012

## MOVE TO IMPROVE

People with rheumatic and musculoskeletal diseases (RMDs) from around the world join together to make their voices heard on World Arthritis Day. World Arthritis Day is an ideal focus for organisations to raise awareness of issues affecting people with RMDs and for individuals to support campaigns.

Read more about the aims of WAD, the 2012 campaign and have a look at the events that are taking place in your country today on [www.worldarthritisday.org](http://www.worldarthritisday.org)



Today is World Arthritis Day!  
How are you celebrating?

See page 3



## My first PARE Board meeting

by Ingrid Pöldemaa

For many years I watched PARE Board members working hard during the Autumn Conference, the EULAR Congress and at lobbying events in Brussels. This year my colleagues in the Estonian Rheumatism Association asked me to stand for the board elections and, after 10 years of working at European level, I decided to apply. There were many candidates for the Board member positions, so I was honoured to be elected. I would like to thank everyone who supported me.

What is expected from a Board member? I had already had a chance to participate in different working groups and so I had some knowledge about PARE's working

methods. But I had a lot of questions before my first official board meeting. The pack of documents that we had to read through before the meeting was the size of the Lord of the Rings book. Was the meeting really only two days, or much longer? Had I missed something? How would we manage to get through all this? These were my first reactions. Then I started to read the documents and all my worries receded. In the Board members' handbook I found valuable information about my future duties. Secondly, I knew generally that there were a lot of PARE projects and activities, but I was reassured to see it all written down in detail. It also made me

realize how hard the PARE Board members had been working all these years. I now appreciate my new board and Secretariat colleagues even more.

Why is PARE unique? I recall the words of one of my colleagues, who took part in PARE activities for many years: "It is like a family and everybody supports and takes care of each other".

I am therefore really happy to be a part of the PARE Board team and I will do my very best for the benefit of people with rheumatic and musculoskeletal diseases in Europe.



## 15th EULAR Autumn Conference for PARE Zurich 2 - 4 November 2012

by EULAR Secretariat

Zurich, the home of EULAR's headquarters, offers the perfect setting to welcome over 120 delegates to the 15th EULAR Autumn Conference for PARE.

EULAR's General Secretary, Professor Nemanja Damjanov, together with Heinz Marchesi, Executive Director, will open the event on behalf of EULAR on Friday 2 November.

The Rheumaliga Schweiz (Swiss League Against Rheumatism) will feature some of their many activities and run a workshop on assistive technologies.

The Conference will introduce updates on the EU Research Framework Programme "Horizon 2020", EUMUSC.net, Patient Research Partners, World Arthritis Day and the new EULAR Strategy.

An internationally successful equestrian competitor, who has first-hand

experience of living with a rheumatic condition, will give an inspirational talk. And there will be a look at the important topic of fundraising.

The "EULAR Document on Physical Activity for people with rheumatic and musculoskeletal diseases (RMDs)" will be available to national organisations for use as a lobbying tool, and a case study from the Netherlands will show how to use the document's recommendations locally. The document will be officially launched on 16 October in Brussels at the EULAR / EFORT Conference: "Preventing Chronic Diseases for a Healthier Europe: The Case for Rheumatic and Musculoskeletal Diseases".

The PARE Board looks forward to another exciting event, a platform for national organisations of PARE to meet, network and be inspired by colleagues.

*"I have attended many conferences ... and I have to say that this was one of the best organised. ... a very high standard indeed"*

*"It was my first Autumn Conference for PARE, but it was much more interesting and enjoyable than all my expectations!! It was GREAT!"*

*Comments from participants at the 2011 Autumn Conference in Athens*



## WORLD ARTHRITIS DAY 2012



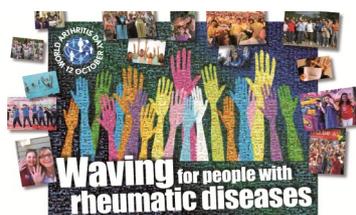
Have you joined the World Arthritis Day Waving Campaign?

**MOVE TO IMPROVE**

For World Arthritis Day 2012 we invited you to submit a photograph or video of people waving to raise awareness of rheumatic and musculoskeletal diseases (RMDs). Over 40,000 of you from 70 countries did so!

The resulting photomontage can now be downloaded at: [www.worldarthritisday.org/resources/organisations](http://www.worldarthritisday.org/resources/organisations)

It is not too late. You can still upload your waving pictures and continue to spread the word. Visit: [www.worldarthritisday.com/waving](http://www.worldarthritisday.com/waving)



Physical activity is vitally important for people with rheumatic and musculoskeletal diseases (RMDs).

Check out the activity of the month on the WAD website: dancing, tai chi, qigong, yoga, swimming, cycling and walking, plus expert views and tips. Be inspired to Move to Improve! Visit: [www.worldarthritisday.org/get-involved/activities](http://www.worldarthritisday.org/get-involved/activities)



## WORLD ARTHRITIS DAY - National activities



**REF**  
Polish Rheuma Federation



World Arthritis Day is celebrated around **Poland** with a variety of events, including outdoor activities.

In Warsaw, the Institute of Rheumatology will hold a day of lectures, workshops and presentations given by health professionals and other experts. Topics include the quality of life of people with RMDs, self-management, patient and disabled rights. There will also be an exhibition of drawings and pictures by children and adults affected by RMDs. Each participant in a World Arthritis Day activity will receive a green ribbon symbolising RMDs.

See: <http://ref.mixxt.pl>



### Cyprus League Against Rheumatism - CYPLAR

Every year CYPLAR organises various activities for World Arthritis Day in **Cyprus**.

This year the event is called "Let's Dance and Exercise with People with RMDs". This will be hosted in one of Cyprus's major shopping malls. There will be live broadcasting by national radio. Health professionals will demonstrate exercises and dancers will invite and encourage people to join CYPLAR members in dancing and exercising. See: [www.rheumatism.org.cy](http://www.rheumatism.org.cy)



The Danish Rheumatism Association



On World Arthritis Day, the Danish Rheumatism Association celebrates "Big Water Day" at swimming pools across **Denmark**.

Guests are given free access to try out AquaPunkt under instruction and supervision of trained lifeguards. AquaPunkt-training consists of exercises in water developed to prevent tender joints and muscles and to give relief to people with rheumatic and musculoskeletal diseases.

For more information about this fun and effective way of exercising visit: [www.gigtforeningen.dk/aquapunkt](http://www.gigtforeningen.dk/aquapunkt)





## A Step Forward: EULAR visit to Bulgaria

by Tsveta Apostolova, President of BOPRD

When we found out that we could invite a EULAR delegation to Bulgaria, we loved the idea. Bulgarian society warmly welcomes working together with major European organisations. So it was a great opportunity for us to arrange events and to try to achieve some of our goals, to exchange experiences and to learn new things.

BOPRD - The Bulgarian Organization for Patients with Rheumatic Diseases - is still young and since there are no similar organisations in Bulgaria there is limited awareness about rheumatic and musculoskeletal diseases (RMDs). The problems we are trying to solve are fundamental: lack of reimbursement means that some people cannot afford to take appropriate medication; and there is difficulty for some in accessing medical support for diagnosis and treatment. Such problems cannot of course be solved in a day, but step by step. And the EULAR visit was one of those steps. We organised a round-table and invited doctors, representatives of state institutions and other organisations including the Bulgarian Ombudsman Mr



Mr Ivailo Kalfin MEP (third from left), Mr Neil Betteridge Vice President, EULAR, representing PARE (fourth from left) and participants at the round-table in Sofia waving in support of World Arthritis Day

Penchev, Secretary of the Bulgarian Medical Union Mr Lenkov, and Chairman of the Centre for Protection of the Rights in Healthcare Mr Katzarov.

One of the people who supported us strongly was Mr Ivailo Kalfin, Member of the European Parliament. After listening to the round-table discussions on the problems of people with RMDs, Mr Kalfin voiced his support for our goals - a better life and treatment for those affected, not only locally, but also at European level. He signed the Brussels Declaration and also waved for the World Arthritis Day campaign.

The presence of the EULAR

representatives at this meeting was not only to show that we are a recognised member of the PARE Standing Committee but also to illustrate how other people with RMDs in Europe are coping with their problems. The EULAR representatives shared their valuable information and experiences, convincing the audience of the importance and impact of RMDs. The event achieved excellent local media coverage.

And the result? We were really surprised how many of the participants in the event stated their support publicly for our organisation and our goals. Afterwards, many suggested working on common projects to support people in Bulgaria with RMDs!

The EULAR visit to Bulgaria therefore achieved much more than we expected - now more people know what RMDs are, we've created new friendships, we've found new partners to support us and to take the next steps with us to improve the life of people with RMDs in our country.

**Thank you**



### A view from Neil Betteridge, Vice President, EULAR, representing PARE

The time spent between PARE board members and our wonderful hosts, the BOPRD, was really inspiring. They are relatively new EULAR members but have achieved so much already, as the meeting we attended with leading policymakers demonstrated. Mr Kalfin has since supported EULAR at the EU level, so the visit has really produced major benefits for all concerned. It was a privilege to be part of it and all at PARE wish BOPRD continued success.



The EULAR visit to Bulgaria coincided with **Scleroderma Day** on 29 June. EULAR representatives took part in BOPRD's awareness-raising event in the centre of Sofia. Brochures on Scleroderma were distributed and participants talked to the public about the disease.

## EULAR EU Affairs activities

In the last few years, EULAR EU Affairs activities have been important in raising the profile of rheumatic and musculoskeletal diseases (RMDs) at the EU level as well as in the achievement of some important policy objectives. Nonetheless, while considerable progress has been made, there is still a long way to go, even within the limited competences conferred to the EU in areas such as public health and social affairs.

In the short and mid - term EU Affairs activities, EULAR has two main goals:

1) to raise further awareness about the relevance of RMDs as



one of the most prevalent, disabling and costly diseases and, consequently, about the need to prioritise actions addressing these conditions;

2) to advocate for the development of concrete policy initiatives aiming to improve the prevention and management of RMDs.

In order to achieve these objectives, EULAR will undertake a number of actions. The events to be held in October 2012 are among the most important ones.

Some of these events, organised in the context of the European Musculoskeletal Health Days, are being co-organised with **EFORT** (the European Federation of National Associations of Orthopaedics and Traumatology), with whom EULAR has recently formed the **European Musculoskeletal Health Alliance**.

Two of these activities, **scheduled for 16 October in Brussels**, are described below.

### Conference on Preventing Chronic Diseases for a Healthier Europe: The case for Rheumatic and Musculoskeletal Diseases

The aim of the Conference is to discuss the implementation of **chronic disease prevention strategies at both the EU and national levels**, paying special attention to the prevention of rheumatic and musculoskeletal diseases (RMDs). During the event, speakers and participants are expected to assess existing initiatives on chronic conditions and RMDs and seek new ways to make prevention strategies a priority in health-related policies.

The Conference will address topics such as: EU and Member States' initiatives aiming to tackle risk factors for RMDs and other chronic diseases; specific initiatives for preventing unhealthy ageing; the role of different players in the prevention of these conditions, etc.

The Conference will bring together high-level EU and national policy makers, public health experts, representatives of patient and health professional organisations, as well as a number of relevant stakeholders.

### Workshop tackling the burden of rheumatic and musculoskeletal diseases through research: Towards a European roadmap for research and innovation in Musculoskeletal Health for the next decade

The aim of the event is to prepare the ground for the development of **a roadmap for research and innovation (R&I) in RMDs**. Such a roadmap would help to address some of the main challenges affecting R&I in these diseases, e.g. the insufficient consensus regarding the priorities for research in RMDs; the insufficient collaboration between different players involved in R&I (scientists, health professionals, people with RMDs, industry, funding institutions, etc.); the lack of integration of national research efforts into a pan-European research strategy; and the insufficient integration of basic, clinical and healthcare research.

Prominent scientists in RMDs, health professionals, patients, representatives of EU and Member States and relevant stakeholders will participate in the event.

As a result of the workshop, it is expected that an action plan for the development of a roadmap for research in RMDs will be approved.

# News from the heart of EUROPE

## EU - OSHA Healthy Workplaces Campaign 2012-2013

Earlier this year, EULAR became a partner of the Healthy Workplaces Campaign 2012 - 2013: Working together for risk prevention. The Healthy Workplace Campaign, co-ordinated by EU-OSHA (the European Agency for Safety and Health at Work) and its network partners in all EU Member States, aims to improve the working conditions of the EU population.

In 2012-13, the Campaign focuses on the importance of management leadership and worker participation for the prevention of work-related accidents and illnesses. Together with EULAR, there are about 60 partners from all over Europe, including governments and their agencies, employers, workers and business associations, as well as different organisations in the health and social fields.

The 2012-13 Healthy Workplaces Campaign is decentralised and is designed to help national authorities, companies, organisations, managers, workers and their representatives and other stakeholders to work together to enhance health and safety in the workplace.<sup>1</sup>

Since rheumatic and musculoskeletal diseases (RMDs) represent about 38% of all occupational diseases, and since several occupational risk factors are to some extent preventable, EULAR has decided to support the EU-OSHA campaign. As part of our commitment, we have agreed to disseminate information of the campaign as well as to organise an event on these topics.

In this sense, we will be organising the workshop **"Workplace**

**accommodations: Tackling risks and management of Rheumatic and Musculoskeletal Diseases for a healthier workforce"**, which will take place on 16 October in the afternoon. The event will be co-organised by EULAR, EFORT and the Fit for Work Coalition. In addition, a representative of EU-OSHA will present at the EULAR-EFORT Conference on Preventing Chronic Diseases for a Healthier Europe (see previous article).

For more information on the campaign, visit the EU-OSHA campaign website: <http://www.healthy-workplaces.eu/en/> or contact our Brussels Office: [Brussels@eular.eu](mailto:Brussels@eular.eu).

<sup>1</sup> EU-OSHA (2012): Healthy Workplaces Campaign 2012-2013 "Working together for risk prevention" campaign.

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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### e - BREAKTHROUGH

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



The Bone and Joint Decade  
Promoting musculoskeletal health  
*Keep people moving*

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