

e - BREAKTHROUGH

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

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Dates for your diary:

- **20 January 2014:** Deadline for Stene Prize national essays to reach EULAR Secretariat
- **31 January at 23.59 CET:** Deadline for abstract submission and bursary applications for EULAR Congress 2014, Paris
- **28 February:** Rare Disease Day
- **15 March:** Stene Prize 2014 Winner announced
- **4-6 June:** 15th EFORT Congress, London
- **11-14 June:** EULAR Annual European Congress of Rheumatology, Paris

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

Planning ahead by Maria Batziou,

Past Chairperson of the EULAR Standing Committee of PARE



Dear Colleagues

We had another successful EULAR Conference for PARE in Reykjavik in November. The warm welcome of our Icelandic hosts set the scene for a very productive event.

However, the absence of our good friend and colleague - David Magnusson, Chair of the Standing Committee of PARE, was painful for all of us. The PARE community had the chance to remember and honour him during the conference.

Even at this very sad time, we are confident that David would wish the PARE work, on which he placed such importance, to maintain its momentum. The Board has forwarded the nomination of Diana Skingle to take over as Chair from January 2014. The EULAR Executive

Committee accepted this under these special circumstances and will ask the EULAR General Assembly to formally ratify this at its upcoming meeting in June 2014.

We are now planning our projects and activities for 2014. Very many thanks to those of you who have responded to the recent e-Breakthrough survey. We always welcome your feedback, comments and views. And we look forward to hearing your innovative ideas for new projects too. It is important that the PARE programme continues to be dynamic and relevant to your needs.

On behalf of EULAR and the PARE Board, I would like to send you warmest wishes for a prosperous and healthy 2014 for you and your loved ones.



IN MEMORY OF DAVID MAGNUSSON

*11.3.1953 – †13.10.2013

Many of you will remember David Magnusson, who tragically died in October after a short battle with cancer.

David developed rheumatoid arthritis at the age of 31 and soon realised that much of the future was in his own hands. He joined the Swedish Rheumatism Association in 1991 to meet and learn from others in a similar situation and soon became an active member. He attended his first EULAR Congress in 2000 and was passionate about the involvement of people with rheumatic and musculoskeletal diseases (RMDs) in EULAR, and in raising awareness amongst policy makers and the public. Among his many roles, David became a member of the EULAR PARE Board in 2005, and was most recently Chair of the Standing Committee of PARE and Vice President of the Swedish Association.

David will be sadly missed by all who knew him, not only for his tireless work on behalf of people with RMDs in the national and international arenas, but also for his enduring good humour and sense of fun.

He is survived by his wife Beryl Svanberg and three daughters.

Marios Kouloumas, EULAR Vice President representing PARE

Abstracts for the EULAR Congress 2014, Paris

by EULAR Secretariat



Now is the time to act if you would like to submit an abstract for the upcoming EULAR Congress 2014 in Paris and have not yet done so. The deadline for abstracts is 31 January 2014 at 23.59 CET.

Marios Kouloumas, EULAR Vice President, representing PARE says "This is a fantastic opportunity for national organisations to display their most recent campaigns and best practice, either as an oral presentation or as a poster. For the first time PARE will organise a professional poster viewing tour in Paris to ensure that the hard work that has been put into creating the posters is better recognised."

The exciting 2014 PARE programme is expected to address a wide range of topics such as healthy eating and nutrition, political campaigning, new technologies and how they affect people with rheumatic and musculoskeletal diseases (RMDs), growing up and growing older with an RMD, travelling, peer support, and lots more. All sessions will have at least one abstract presentation and of course there will again be the popular abstract session featuring a variety of activities.

All you have to do is to go to the EULAR website www.eular.org – access the Congress website from there and carefully read the instructions about the abstract submission process. If you have any questions please do not hesitate to get in touch with the EULAR Secretariat at birte.gluesing@eular.org Finally - do not forget to apply for your travel bursary at the same time! We look forward to seeing all your abstracts. Good luck!

16th EULAR Autumn Conference for PARE Reykjavik, 15-17 November 2013

by EULAR Secretariat



Prof. Maurizio Cutolo (left) and Marios Kouloumas (right) together with the Opening Plenary Session speakers from Iceland (from left) Dóra Ingvadóttir, President of Gigtarfélag Iceland, Anna Lilja Gunnarsdóttir, Permanent Secretary, Icelandic Ministry of Welfare, Madame Vigdís Finnbogadóttir, Former President of Iceland, Prof. Stefán Ólafsson, Professor of Sociology, University of Iceland

It is always exciting to see if a new concept is working. The 16th EULAR Autumn Conference for PARE held in Reykjavik, Iceland, 15-17 November 2013 was living proof that it is worthwhile changing even a very successful layout and try something new.

The 2013 Conference saw fewer plenary sessions, new formats and 16 different workshops. The 125 delegates, including 25 Icelandic representatives, enjoyed the variety of sessions and new networking opportunities like the

opening 'icebreaker' and the poster rally.

Prof. Maurizio Cutolo, President of EULAR, gave the welcome address on behalf of EULAR and inspired the audience during his interview with Marios Kouloumas, EULAR Vice President, representing PARE. "It was my first time at the Autumn Conference and I was very impressed by the enthusiasm and positive energy of the delegates. Our hosts the Icelandic League Gigtarfélag did a great job. It was a pleasure for me to be involved."



Delegates exploring ideas in one of the Conference workshops

It was the first time that part of the conference was streamed on live media and there was an opportunity to follow the Friday morning plenary session on the internet.

A full report of the Conference is being produced to capture the main findings and outcomes from all the many discussions and it will soon be shared with all delegates and on the EULAR website.



Participants of the 16th EULAR Autumn Conference for PARE, Reykjavik

Comments from participants

"The interactive set up of the conference was very good. Also, the networking opportunities were very useful."

"Lecture of Maurizio Cutolo was wonderful, a pleasure to listen to him."

"The content and moderation of the workshops that I've attended were excellent and very useful and I'm sure that my organisation will use the information and the knowledge that I've gathered."



'Vision 2043 - making a change for the future'

by EULAR Secretariat



As part of the Healthy Ageing campaign, World Arthritis Day recently launched 'Vision 2043 - making a change for the future', a competition to help identify ideas, innovations and design solutions that could make the world a more inclusive place.

If you have a rheumatic or musculoskeletal disease (RMD), or care for someone with an RMD, consider the one thing that you would most like to change to make life better, and what could be done to solve it. Your solution could be anything from a simple gadget to a grand plan. You could help millions of people with RMDs by solving some of their daily challenges, and have a chance of winning a great prize. Visit www.worldarthritisday.org/vision2043 for more details.

There are five themes in the competition, and an open category:

- **Built environment** – homes and cities of the future
- **Mobility, travel and transport** – local and global
- **Life enhancement** – gadgets and apps
- **Employment** – workplace and remote working
- **Health** – treatments and self-management

Competition details:

- Open to everyone over 18 years of age (see *Terms & Conditions on WAD website*)
- Ideas, innovations and designs can be existing items or original inventions
- Entries can be represented in a photograph, video, soundtrack or in words;
- All visual entries should be accompanied by a brief written explanation in English

National organisations can help promote the 'Vision 2043' competition by:

- Featuring it on their websites, in their publications and via local and social media
- Contacting colleges running courses in product, industrial and computer related design, architecture and town planning bodies, employers' organisations, and companies developing health technologies and treatments etc.

A pack of promotional materials for national organisations is available at: www.worldarthritisday.org/tools-for-you/organisations

Closing date **Friday, 25 April 2014**

Don't let your good ideas go to waste
Enter the competition today! Good luck!

Living better ageing well

Deutsche Rheuma-Liga celebrates its volunteers on World Arthritis Day 2013 by Dieter Wiek



Most of the activities and work of Deutsche Rheuma-Liga are run by volunteers. More than 10,000 people, most of them with arthritis, are active in the organisation. They lead the organisation as board members, they give information and advice, they organise exercise groups and information days, and they represent the interests of arthritis patients in discussions with decision makers.

This year Deutsche Rheuma-Liga decided to honour its volunteers for their commitment on World Arthritis Day. A special button, a thank-you-card, pennants for desks as well as posters and flyers drew attention to their volunteer work. Internet and Facebook pages of the organisation, and a short film, showed people with arthritis actively raising awareness about arthritis and giving their time and energy to help others and, by doing so, often helping themselves as well.



Deutsche RHEUMA-LIGA
• GEMEINSAM MEHR BEWEGEN •





Greece and the economic crisis

by Katerina Koutsogianni, The Arthritis Foundation of Crete



Greece has been seriously affected by the economic crisis. The government has had to take measures to tackle the crisis and meet budget deficit reduction targets. The reduction of salaries and pensions, tax increases, and budget cuts in sectors such as education and health, are having a serious impact on the health system's capacity and sustainability.

Issues like access to care, free medications, early diagnosis, appropriate rehabilitation and social support for people with rheumatic and musculoskeletal diseases (RMDs) are threatening services. Data from a 2012 survey illustrates the problems that people with RMDs are facing:

** 1 in 4 patients experienced problems accessing a rheumatologist due to severe delays in booking an appointment, and the long distance and difficulties of travelling to and from the clinic.*

** 1 in 5 patients with rheumatoid arthritis (RA) indicated that their state of health had worsened due to loss of, or delay in, their treatment.*

** 1 in 4 patients with RA had asked their doctor for a change in treatment due to the difficulty in obtaining their original medication.*

All doctors agreed that reduced access to effective medication could result in deterioration of the patient's health status, and 42 % of doctors reported that it might also increase the need for hospitalization. In practice this means that a large number of the population (more than 300.000 have an RMD) will be unproductive and unable to live independently in the near future. In the longer term, the burden on society will increase significantly.

However, despite these gloomy prospects, it is perhaps the right time to review the past practices of the health care system. It is also the right time for patient organisations to be actively involved in the decision-making process related to healthcare services, and in the design of a fair and more inclusive healthcare system.



“Move to Improve” Fashion Show

by Marija Kosanovic,
Association of Rheumatic Diseases Patients of the Republic of Serbia



Every year the Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS) celebrates World Arthritis Day as a central event in our activities calendar. In 2012 we organised a fashion show.



M. Kosanovic and the journalist Z. Mihajlovic were the first to “break the ice”

We aimed to raise public awareness about issues and needs of people with rheumatic and musculoskeletal diseases (RMDs). Through the visual effects of the fashion show, we wanted to bring the public closer to understanding the effects of RMDs, and to explore and promote opportunities for designing clothes for people with RMDs.

Our fashion show, “Move to Improve”, held during the 21st Maybelline Fashion Selection event, was organised in co-operation with Belgrade Design District and the Serbian media. The models were volunteers – members of ORS with RMDs - who were escorted to the stage by journalists from First Serbian Television. They wore clothes that had been specially designed to suit people who have difficulty dressing themselves. The young designers did their job superbly. They created simple, usable, modern clothes without buttons, zippers or ribbons.



M. Aleksic and her partner staged a performance

The show attracted great media attention, with reports broadcast by 15 TV and 6



And there was something for mature people too J. Saric

radio stations. Also, 17 print media and 25 internet sites published stories about the show. The daily newspaper “Blic” organised an internet competition for the best fashion show during the Maybelline event. More than 1.3 million people voted. With 62% of the votes, “Move to Improve” won the top prize in this prominent fashion event in Serbia.

Dr M Lapcevic, President of the ORS, receiving the Best Fashion Show Award



EULAR Public Affairs Activities

by EULAR EU Office Brussels

As in previous years, EULAR was very active in Brussels around World Arthritis Day 2013. Two main events were organised this year:

- The Conference “Chronic diseases and health care delivery 2020: The challenge of rheumatic and musculoskeletal diseases. Findings, lessons and perspectives from the eumusc.net project”
- The 12th meeting of the European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs), which focused on “New European Union (EU) Data Protection Legislation: Consequences for health research”



Conference delegates at the European Parliament



eular



Conference



Presentation at the Conference by EULAR President Prof. Maurizio Cutolo

The Conference was held at the European Parliament and at the Thon Hotel EU on 17 October. It was hosted by Paul Rübig – Member of the European Parliament (MEP) from Austria - and had the support of the Lithuanian Presidency of the EU. The purpose of the event was to present the results and recommendations of the eumusc.net project (www.eumusc.net) and to discuss

how to implement further its results in EU Member States.

The eumusc.net project (an initiative that was co-sponsored by EULAR, and undertaken with the support of the European Commission) aimed to raise and harmonise quality of care and to enable equity of care of RMDs across EU Member States. To this end, the project developed standards of care of the main RMDs as well as methods and tools that will allow Member States to measure the burden of RMDs in their own country, and the quality of care that people with RMDs receive.

The Conference was an excellent opportunity to present and discuss the evidence collected by eumusc.net that proves that RMDs are one of the most burdensome chronic conditions affecting European societies. It was also a good opportunity to raise awareness of the need to implement concrete actions against these diseases i.e. implementation of the eumusc.net results.

About 120 participants from 30 countries attended the event, including representatives of the European

Commission, the European Parliament, the EU Council, the World Health Organisation, a number of patient, clinician and health professional organisations, and other stakeholders.



Key stakeholders, including people with RMDs, taking part in the Conference in Brussels in October 2013

European Parliament Interest Group on RMDs

In its capacity as Secretariat of the European Parliament Interest Group on RMDs, EULAR organised the meeting “New EU Data Protection Legislation: Consequences for health research”.

The aim of the event was to discuss the new regulation on data protection that was going to be voted on a few days later at the European Parliament Committee for Civil Liberties, Justice and Home Affairs. The relevance of this new regulation for the RMD community is that it may hinder health research activities, since – among others - it would impose rather restrictive conditions for the use of patients’ data in research.

The event was hosted by MEP Jim Higgins (Ireland) and MEP Takis Hadjigeorgiou (Cyprus), with the participation of the European Commission and representatives of more than 20 organisations.

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For more information about these events, visit the EULAR website (www.eular.org) or contact the EULAR Brussels Office (Brussels@eular.eu)

Remembering David Magnusson



David Magnusson was an outstanding friend and colleague and he will be long remembered by the EULAR community and beyond. His family was extremely touched by the many people from around Europe who sent their condolences, including people with RMDs, PARE organisations, health care professionals and doctors.



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



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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