

eular

SPECIAL ISSUE July 2013

e - BREAKTHROUGH

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

14th ANNUAL EUROPEAN CONGRESS OF RHEUMATOLOGY 12 - 15 JUNE 2013 MADRID



Gracias Madrid! L'année prochaine, Paris!

Hello everyone!

Another successful EULAR Congress. Over **14,000 delegates** from all over the world attended the 14th Annual European Congress of Rheumatology 12-15 June 2013 in Madrid!



We thought that it would be interesting to capture the atmosphere, the programme and the highlights of the Congress in a supplementary e-newsletter for those of you who did not have the opportunity to experience it all first hand.

This year's PARE programme was outstanding and all its sessions were welcomed enthusiastically, not only by PARE delegates but also by health professionals and clinicians. Many of the PARE sessions were so well supported that the room was unable to accommodate everyone who wished to attend. It was unfortunate that the air traffic strikes in France prevented some speakers and chairs from travelling to Madrid on the first day of the Congress. However, as you will see on the following pages, the Congress was exciting, innovative and tremendously successful.

However, without the people who worked hard to prepare this Congress no success would have been possible. I would like to thank all those who contributed and made it possible: EULAR in general and in particular Ernst Isler, Congress Manager, and MCI; the speakers, the chairs, the Scientific Committee and many, many more who participated in delivering such a successful Congress and a thought-provoking and informative PARE programme.

Inevitably, preparations begin immediately for the 2014 EULAR Congress in Paris. Please help us to develop another PARE programme that addresses the topics and issues that are of high importance to you. It is only by sharing your thoughts and comments that we can continue to develop and improve our sessions and networking opportunities. Evaluation forms can still be obtained from the EULAR Secretariat: birte.gluesing@eular.org If you have not yet done so, please do send us your feedback.

Maria Batziou
Past Chairperson of the EULAR
Standing Committee of PARE

Dates for your diary:

**EULAR
CONGRESS**



**11-14 JUNE
2014
PARIS**

New Appointments in EULAR



EULAR President elect, Prof. Gerd Rüdiger Burmester



Prof. Christina H. Opava, Vice President, EULAR, representing Health Professionals in Rheumatology together with Vice President, EULAR, representing PARE, Marios Kouloumas



EULAR Treasurer, Prof. Johannes W. J. Bijlsma



EULAR General Secretary, Prof. Nemanja Damjanov, re-elected for second term

EULAR Congress Madrid

A message from the new EULAR Vice President representing PARE, Marios Kouloumas



Neil Betteridge (left) and Marios Kouloumas

It is a great honour for me to be elected as the new EULAR Vice President of PARE and to succeed Neil Betteridge. I would like to thank him for all he has done for people with rheumatic and musculoskeletal diseases (RMDs) and congratulate him on a very successful term of office.

I believe that EULAR's strength is based on its members: the patients, doctors and the health professionals who work together with common objectives and goals. This is very important and also unique in that EULAR represents all of the RMD community across Europe.

The new EULAR Strategy "Vision 2020" gives a comprehensive framework and a common platform to improve the prevention, care, rehabilitation and research of RMDs and to reduce the burden of rheumatic diseases on the individual and on society. RMDs should be a priority on the European Union (EU) health agenda, reflected in all decisions of the EU institutions, and recognized as an equivalent to other major chronic diseases. In a series of important initiatives aimed at ensuring the full inclusion of persons with disabilities and the enforcement of their rights, EULAR also aims to lobby for the implementation and mainstreaming of the UN Convention on the Rights of Persons with Disabilities.

I would like to assure you that I will work very hard and co-operate with all EULAR and national representatives in order to achieve the aims of "Vision 2020". Patient organisations have a central and active role to play in this and EULAR will facilitate their efforts in achieving our collective goals.



The PARE Booth

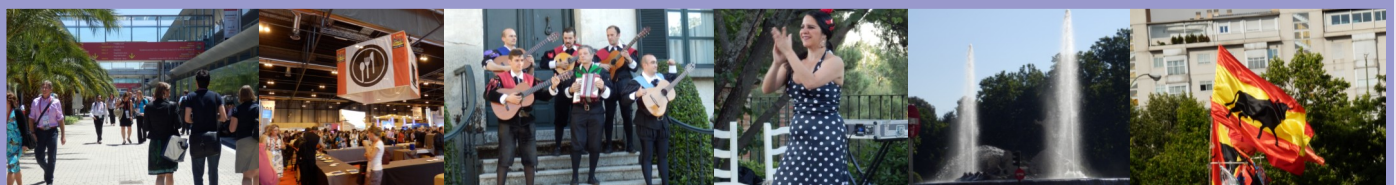
The PARE Booth was extremely popular this year and ideally located close to the EULAR and the Health Professionals booths.

It was again a central meeting point and hub for all PARE delegates and equipped with excellent information about PARE's programmes and showcasing the great variety of work done by EULAR member organisations. A huge thank you goes to Dragan Chichikj



and Emmi Myohänen who were the volunteers this year, staffing the booth and doing a wonderful job in making the activities of PARE better known to the on-site audience.

A quiz initiated by Dragan Chichikj revealed that the numbers of people affected by RMDs in Europe, and the associated economic and social impact of these diseases, were seriously underestimated by delegates.



EULAR Congress Madrid

Congress Report by EULAR PARE Congress Task Force*

Every year the four days of the EULAR Congress are over in the blink of an eye. Madrid was no exception. It was exciting for the programme team to see the sessions, carefully planned and developed over a year, finally coming to life. Expectations were high.

The Madrid Congress attracted so many excellent speakers that the overall programme was of particularly high quality, and the delegates responded to the sessions with enthusiasm. It was an absorbing and successful four days.

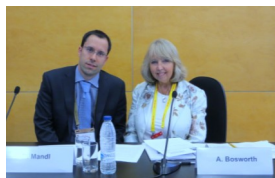


Mette Toft (second from left), winner of the 2013 Edgar Stene Prize

At the Opening Plenary Session, Maxime Dougados, President of EULAR, announced the winners of the prestigious 2013 EULAR awards. On stage to receive the Edgar Stene Prize 2013 was Mette Toft from Denmark who won the

annual writing competition with her essay "Growing up or growing older – my secret for healthy ageing with a rheumatic or musculoskeletal disease". Mette went on to give an inspirational talk to the delegates in the joint session on Healthy Ageing. Congratulations Mette!

The PARE programme featured talks from clinicians and health professionals in almost every session. This attracted PARE delegates and a very broad audience from the other EULAR pillars. For the first time it felt that the activities of PARE were not only valued by the attending delegates but were also an integral and unmissable part of the whole Congress. It was inspiring to see information about the work of the PARE organisations reaching a much broader audience. There was a large number of excellent abstracts for the PARE sessions. Those that could not be accommodated as oral presentations were included in the poster area giving a fascinating insight into the wide range of activities carried out by



Ailsa Bosworth (right), Chief Executive of the UK National Rheumatoid Arthritis Society chairing the session "Latest advances in treatment and management of RMDs" together with her colleague Dr Peter Mandl, representative of EMEUNET, the Emerging EULAR Network of young clinicians and researchers in rheumatology



The PARE Abstract Session "From abstract to concrete – the variety of activities in the PARE organisations" heard 8 highly attractive presentations. Pictured from left to right are the presenters and the session chairs: M. de Wit (Netherlands), J.L. Garrido-Castro (Spain), E. Udras (Estonia), K. Betteridge (UK), U. Faubel (Germany), S. Bozhinova (Bulgaria), J. Holch (Denmark), H. van Duijn (Netherlands), A. Carlsson (Sweden) and A. Bosworth (UK)

national organisations. The organising team would like to thank everyone who contributed.

Besides the busy formal programme there was also time for networking at the PARE Booth and outside in the sunshine after the Opening Plenary Session. The PARE Networking Dinner and the EULAR Congress Dinner also offered opportunities to interact informally with speakers and colleagues, and to discuss the variety of information gathered during the day.

The PARE team is extremely grateful to Ernst Isler, the EULAR Congress manager, probably the busiest person at the Congress, who took time on the first day of the event to give a briefing about the Congress venue, access and logistics, and who generally smoothed the way for the PARE delegates.



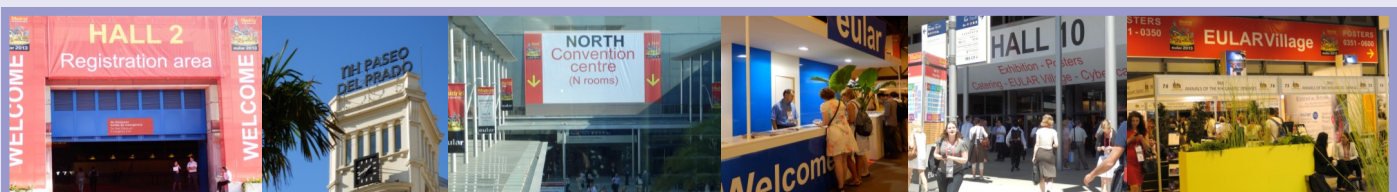
Chairing the session "Gender Differences in care and treatment" Dieter Wiek (Germany) and Snezhana Bozhinova (Bulgaria)



Marija Kosanovic and Zivan Pavlovic from Serbia wearing their outfits which were designed for people with RMDs in co-operation with the designers of the Belgrade Fashion Week – a truly inspirational co-operation

Finally, a huge "Thank You" goes to all the delegates who participated tirelessly in the sessions, contributed to the open and friendly atmosphere, and who were key in stimulating exciting discussions and exchanges with the experts.

*EULAR PARE Congress Task Force members: Neil Betteridge, Maria Batziou, Marios Kouloumas, David Magnusson



EULAR Congress Madrid

Some examples of the programmes and achievements of national organisations illustrated in the vibrant PARE poster display



A personal view of the Congress by Kate Betteridge



I was privileged to be asked to present highlights from the PARE programme to the health professionals on the final day of the Madrid Congress – quite a responsibility when you consider the quality and diversity of the sessions and the speakers.

My challenge then was to look for commonalities which I could pull together to present as only ‘**3 take home messages**’. It was clear from quite early on that a few issues kept coming through time and again. For a while I felt a bit deflated because we have known these issues for a while. Maybe we were no further forward? The joy of listening to all our speakers, though, was that plenty has changed, and perhaps now things are a lot clearer and more of us are on the same page.

So what were my 3 take home messages? To me they were:

1. **Ageing is not just about physical health** – it’s about emotional well being, feeling fulfilled, looking after ourselves so that when we do get older, we are as happy and healthy as we can be.
2. **We all have to try to do things differently** – whether this be politicians, clinicians, health professionals or patients, we all have to adjust to the changing environment and find different ways of approaching rheumatic and musculoskeletal diseases (RMDs).
3. **Collaboration is the only way forward** – to stand out we need to work together. We need to ‘join the dots’ and make sure that the improvements we make in the treatment of RMDs translate into people with RMDs being able to live independent and fulfilled lives outside of the clinic.

The overarching impression I took away with me was the will and determination of individuals, national organisations, clinicians, health professionals, and specialists of all sorts to work together to promote RMDs and to provide support to the people who are living with them every day.

What you said about the Congress:

“[I liked] the very active participants at the session Gender Differences. We should encourage discussions.”

“I have learned a lot and brought a lot of information and examples to share.”

“I was very satisfied with the PARE Programme! It was great not to have sessions so early in the morning. Overall the sessions were very interesting. Great conference programme! Congratulations!”

“It was the first time that the topics of the PARE sessions were so interesting. I did not hesitate for a moment to attend almost all of them.”

“Very well planned ... I had the time to meet other delegates and talk a lot between sessions.”

“Was impressed by the overall set up of the Congress this year. I can say it was the best of the total three I have attended.”





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



The Bone and Joint Decade
Promoting musculoskeletal health
Keep people moving

EULAR supports the BJD: www.boneandjointdecade.org