

eular

SPECIAL ISSUE July 2015

e - BREAKTHROUGH

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



16th ANNUAL EUROPEAN CONGRESS OF RHEUMATOLOGY 10 - 13 JUNE 2015 ROME

Arrivederci Roma e molte grazie!



Dear members of the PARE community and PARE friends,

More than 14,000 delegates from 120 countries attended the 16th Annual European Congress of Rheumatology from 10 - 13 June 2015 in Rome. Clinicians, health professionals, physicians, people with rheumatic and musculoskeletal diseases and scientific researchers came together in the marvellous ancient city of Rome to experience and discuss the development and progress in the treatment of rheumatic and musculoskeletal diseases (RMDs).

The PARE programme offered brilliant scientific and health professional speakers, and experienced people with RMDs. Representatives from our member organisations broadened the perspective by contributing the angle of people with RMDs. The attendance of participants from the non-PARE community proved the attractiveness of combining practical research, patient-centred care and consideration of what people think and how they feel when living with an RMD.

At the Opening Ceremony the President of EULAR Prof. Maurizio Cutolo awarded the Edgar Stene Prize



to Charlotte Secher Jensen from Denmark (left top) for her essay entitled "Living in the moment". This year's PARE abstract winner comes from Denmark as well: James Rickmann (left below) received the award for an innovative smartphone app named Rheumabuddy that empowers RA patients.



I would like to express my thanks to everyone who contributed to this informative programme, and to those who worked hard at the PARE booth, PARE's place of meetings and lively discussions.

I hope that the richness and diversity of information has inspired and encouraged you personally and will support the work in your organisation to improve the quality of care for people with RMDs.

I am looking forward to seeing you in London 2016.

Dieter Wiek
Chairman of the EULAR
Standing Committee of PARE

Dates for your diary:

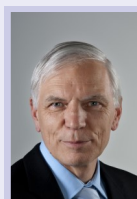


**EULAR
CONGRESS
8 - 11 JUNE
2016
LONDON**

New Appointments in EULAR



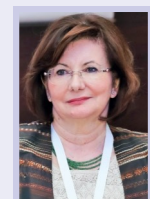
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*EULAR President-elect
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*EULAR General Secretary
Prof. Ruxandra M Ionescu*

EULAR Congress Rome

View from the Health Professionals by Prof Tony Redmond, Chair of the EULAR Standing Committee for Health Professionals in Rheumatology



New HP members Andrea Domján (Hungary), Françoise Alliot-Launois (France), and Lurdes Barbosa (Portugal) after their membership approval at the General Assembly

The Rome Congress was a great one for Health Professionals (HP). We welcomed three new member countries and bade a fond farewell to outgoing chair Sue Oliver. Even before Congress itself was up and running, the Scientific Committee had been hard at work starting the planning for the programme for the London 2016 Congress. This will include some stimulating HP sessions and some novel joint sessions which might be relevant and interesting for PARE members also.

There were several highlights in the HP Congress programme for Rome, not least Sam Dickinson from Google who had everyone thinking about being more creative in finding solutions. The submitted abstracts were also of a very high standard this year with consistently excellent oral sessions and a very strong showing in the poster hall.

Finally, of course, we could not report on a Congress in Rome without mentioning the social side. From fabulous dinners to historical

highlights, Rome provided a wonderful backdrop to EULAR 2015 and, a few travel limitations notwithstanding, made for a memorable week.



Members of the EULAR Standing Committee for Health Professionals in Rheumatology - High 5 for World Arthritis Day

The PARE Booth

Once again the PARE Booth at the EULAR Congress in Rome was the face of PARE where our delegates, health professionals, clinicians and other visitors had the chance to learn about PARE activities and the new World Arthritis Day (WAD) "High 5" campaign. They participated in the awareness raising campaign with great enthusiasm and the photos of them "High5ing" were uploaded on the newly launched WAD website and on social media. Our thanks to everyone who took part.



Special thanks also to the PARE Booth team: our Italian MCI colleague Giorgio Coen Cagli who worked hard with exceptional dedication; and our volunteers Lena Andersen, Jolanta Grygielska, Nele Caeyers, Ursula Faubel, Elsa Mateus and Jürgen Clausen who, despite their busy schedules, contributed with great devotion and enthusiasm.

Many of our member organisations had the opportunity to display their own materials at the PARE Booth and share their activities with an international audience, and inspire other PARE delegates. Moreover, the PARE Booth served as a place where PARE delegates could rest, meet and socialise with delegates from all over the world and enjoy Italian coffee and delicious food.



Congress Report

by EULAR PARE Congress Task Force*

The eternal city hosted another very successful EULAR Congress in June and inspired its delegates with the latest findings in the field of rheumatic and musculoskeletal diseases (RMDs).

The wide-ranging PARE programme offered a variety of sessions including a warm welcome from Ernst Isler, EULAR Congress Manager, and his colleague Simone Lüscher, EULAR's Deputy Congress Manager, who helped PARE delegates to find their way around the complex and busy Congress venue.

In addition to those pictured, PARE sessions included the importance of carers and the family, top tips on pregnancy and RMDs, insights into how important the collaboration between GPs and rheumatologists is for the patient, and 'Championing Work'. Young PARE introduced their Youth Strategy, and Charlotte Secher Jensen read her winning Stene Prize essay, moving the audience greatly.



A Bosworth and JN Dachicourt (in front row) chaired **Lost in the system – how to use innovative care to bring health services back to the patient** with contributions from (left to right) R Bengoa, G Korevaar, T Vliet Vlieland, S Blackburn and U Faubel



Building sustainable relationships between patients and researchers was chaired by I Kjeeken and M de Wit (left and right) with presentations given by (left to right) J Primdahl, U Bergsten, L Andersen, A Higginbottom and I de Keyser

The Abstract Session was the highlight for many delegates as sharing best practice is of such value for everyone. The "Lupus Secrets" were revealed in the 'What's New' session giving very concrete, easy to understand and practical advice for people affected by Lupus

Erythematosus. The session also heard the latest developments in the use of glucocorticoids and an introduction to the European Medicine Agency (EMA) and its position on biosimilars. After a successful start in 2014, PARE again ran two Poster Tours in Rome. Ideally located next to the PARE Booth these were a real asset to the overall programme and were enjoyed greatly by the attendees.

"The Scientific Committee, in which the four of us plan the PARE Programme, works very hard all year long to provide interesting and inspirational content for our sessions. But it is our speakers and abstract presenters who bring these sessions to life. We would like to thank all those who have been



Measuring success - How to evaluate the Impact of your campaign featured talks by Maria Ekroth (2nd left), J Aaps (3rd left), JA Holch, J Clausen and A Stara and was chaired by K Lerstroem and E Mateus (left and front)

actively contributing to the 2015 PARE programme. It is in the end their expertise and knowledge which make the Congress such a success and so special each year" says Marios Kouloumas, EULAR Vice President, representing PARE, on behalf of the 2015 PARE programme planning team.

There is never enough time for every hot topic to be featured during these busy Congress days! Luckily there is the next Congress to address them! The 2016 PARE programme is already being compiled and London is looking forward to welcoming you all again next year!

*Task Force members: Maarten de Wit, Marios Kouloumas, Diana Skingle, Dieter Wiek



A message from ANMAR - Italian Association of People with Rheumatic Diseases

Dear friends of PARE,

It was an honour to welcome you to Rome. ANMAR's representatives in PARE now include Ugo Viora on strategic issues, Sara Severoni on social topics and Silvia Ostuzzi on youth issues. There is much work to do. Our goal is early detection and ensuring that effective treatment for RMDs is seen as an investment, not a cost. We are also working to create a youth group to address themes related to the world of young adults.

With your friendship, and by working together, we will achieve many important and common goals.

Renato Giannelli, President ANMAR



EULAR Congress Rome



A personal view of the Congress

by Elsa Mateus,
Portuguese League
Against Rheumatism

The impressive numbers attending the Annual European Congress of Rheumatology EULAR 2015 - over 14,000 physicians, health professionals, scientific researchers, patient group members, and industry representatives - illustrate the overwhelming importance of the EULAR Congress.

It is a privileged opportunity for networking from which, I am sure, every participant returns home with new ideas to implement. With so many things happening at the same time, in the same place, deciding where to be can be a difficult task. Even so, the PARE Sessions Programme provided us with a good overview of the Congress topics, focusing on patient advocacy. In this year's sessions it was possible to reflect on patient involvement in research, and on the importance of work as a meaningful outcome for health care interventions. These perspectives are crucial for changing the "burden" of disease into one of "investment", with the return on that investment being the patients' ability to contribute to society and to the economy, which benefits us all.

The need to move towards an integrated health care model was stressed. There were several examples about empowering, supporting and educating patients in self-management and in adopting a healthier life style. The importance of the family as an informal structure of care was also noted; the family can be greatly affected when one of its members suffers from a RMD. The Young PARE strategy provided us with a glimpse of the future generation to whom all these concerns will assume an even greater importance as they experience an extended period of living with a RMD.

Besides the high quality of the PARE programme, and of the oral presentations and posters exhibited, the patients' involvement in the Congress programme is now recognised as valuable and important. And for me, that was the highlight of this year's Congress.

The PARE Poster Tours



Feedback from PARE delegates

"My highlight was the abstract sessions where we could hear about the great work of individuals and organisations in their own countries."

"The session that I got most from was the 'Taking Control' session. Lots of information and new ideas."

"The PARE programme is growing from strength to strength every year."

"I must highlight the posters, because I think they have brought us new insights."

"Overall, I must highlight that there seems to be more awareness of how useful patients' perspectives and involvement are in improving research and solutions for a better way of living with RMDs."





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