

eular

SPECIAL ISSUE July 2014

e - BREAKTHROUGH

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



15th ANNUAL EUROPEAN CONGRESS OF RHEUMATOLOGY 11 - 14 JUNE 2014 PARIS

C'était magnifique!



Dear colleagues!

Once again the EULAR Congress brought together people with rheumatic and musculoskeletal diseases (RMDs), health professionals and clinicians to showcase new ideas, innovation and best practice in the world of rheumatology. Over 13,000 delegates from 129 countries attended the 15th Annual European Congress of Rheumatology 11-14 June 2014 in Paris!

The PARE programme was packed with high quality sessions, including expert and professional speakers, complemented by abstracts and presentations by members of PARE national organisations from around Europe. Your personal experiences, practical research, and patient-centred focus brought fresh and valuable insights into how people with RMDs are perceived, and highlighted the issues that are important to their lives.



It was a real thrill at the Opening Plenary Session to see the President of EULAR Maurizio Cutolo present the 2014 Edgar Stene Prize to Marinka Stein Due Sørensen (Denmark) (photo far left) and the first ever PARE abstract award to Rolf Greiff (Sweden) (photo left).

I hope that this short e-magazine will remind you of the superb array of information that was made available during the Congress and will trigger you to use it to introduce further innovative programmes and approaches in your national organisations.

My sincere thanks go to the very many people who contributed and worked so hard to make the PARE programme at the Congress such a resounding success. Roma l'anno prossimo!

Diana Skingle

Chairperson of the EULAR Standing Committee of PARE

Dates for your diary:

EULAR
CONGRESS



10 - 13 JUNE
2015
ROME

Congratulations to the new EULAR Standing Committee Chairs-elect

Education and Training

Prof. Annamaria Iagnocco, Italy

Paediatric Rheumatology

Prof. Tadej Avcin, Slovenia

Clinical Affairs

Prof. Ronald van Vollenhoven, Sweden

Epidemiology and Health Services Research

Prof. Axel Finckh, Switzerland

Health Professionals in Rheumatology

Prof. Anthony Redmond, United Kingdom

PARE

Mr Dieter Wiek, Germany



Congress Report by EULAR PARE Congress Task Force*

Every year the EULAR Congress is an extraordinary event but Paris was very special. It was the first time that PARE hosted a formal Poster Tour. Twenty two presenters shared their poster and engaged in professional discussions with the audience. Marios Kouloumas who led the first PARE Poster tour commented: "This is a clear asset to the PARE programme and the enthusiastic feedback shows a clear vote to continue the tours at the Rome Congress."

The 2014 PARE programme presented a kaleidoscope of topics. Fantastic speakers introduced hot topics such as biosimilars and orphan drugs, the role of vitamin D, safe travelling with rheumatic and musculoskeletal diseases (RMDs), peer support, the impact of the economic crisis and strategies on how to cope with growing up with an RMD. In several sessions almost every seat was taken. Attendees were not only patient representatives but also health professionals and rheumatologists. "The session concept involving all three EULAR pillars gives the PARE sessions added vibrancy and visibility. We would like to thank all the speakers and abstract presenters as it is the quality of their contributions that is the key to our success" said Diana Skingle, Chair of the Standing Committee of PARE and member of the Congress Task Force.



J Church (left) and S Makri (second from right) chaired the exciting PARE abstract session in which speakers presented a variety of activities and projects: (from left to right) A L Dorjée, S J Blackburn, L Carton, R Greiff, M Sørensen, U Viora, O Hoare, and B H Boteva



The session *I-patient - the role of smart decision making* was chaired by I Pöidmaa and L van Nieuwkoop (second and third from left) and heard inspiring accounts from (left to right) M Tumim, J Grygielska, D Horgan, M Dougados and R Alten

The diversity of the audience guaranteed lively and interesting discussions, and in many cases the exchange between speakers and audience continued long after the formal session had ended. We would also like to thank all the chairs of the PARE and Joint Sessions for their great support – their time-keeping, discussion guidance, and positive and motivated participation ensured a highly successful and professional programme. PARE would also like to thank Ernst Isler and his team from MCI

for the careful thought and planning around the needs of people with RMDs during this huge event.

Of course networking played a key role during the four busy days in Paris and the programme offered some great opportunities to catch up with old friends and to make new ones. The PARE Networking Dinner hosted by AFLAR offered a lively and friendly atmosphere and new faces were warmly welcomed and integrated into the community. Thank you AFLAR for your hospitality!



Healthy Ageing I - growing up with an RMD, chaired by J-N Dachicourt and N Betteridge (first left and second right), gave a great insight into the life of young people with RMDs, the role of the parents and the importance of a well managed transition, with talks by (left to right) L Kullamaa, B Markus, L van Nieuwkoop, S.O'Shaughnessy, M Backström

Thank you too to all the delegates who participated so positively and enthusiastically in the PARE sessions. Planning for the next Congress has already started. We look forward to seeing you all in the Eternal City of Rome in 2015!

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

A message from Jean-Noël Dachicourt, Director, AFLAR French League Against Rheumatism



"AFLAR, the French League Against Rheumatism, was extremely proud that the EULAR Congress was hosted in Paris this year. We were delighted that we had the opportunity to see so many representatives of PARE organisations visiting our stand in the Congress Centre. We met doctors and patients from a variety of countries each bringing their own particular perspectives on rheumatic and musculoskeletal diseases (RMDs). We were especially happy to host a relaxing networking dinner for all the PARE delegates at the Opera Concorde Restaurant.

The EULAR Congress is a fantastic event for people with RMDs to learn about the latest research, to listen to interesting presentations from experts, and to form strong bonds with other national organisations, clinicians and health professionals."



EULAR Congress Paris

The PARE Booth

by EULAR Secretariat

At every EULAR Congress, the PARE Booth is the hub of PARE activities and the voice of PARE within the Congress. In Paris it was in a very convenient location, close to the PARE session room, and was a focal point where PARE delegates could rest, meet, communicate with each other, and interact with delegates from around the world.

Hundreds of Congress participants had the opportunity to visit the Booth and to learn about the PARE community and its activities. They also had the chance to enter the popular World Arthritis Day competition "Vision 2043" - over one hundred entries were made during the Congress.



The PARE Booth team (left to right) Lembe Kullamaa, Jolanta Grygielska, Thibaut (from MCI), Maria Batziou and Codruta Zabalán



The PARE Booth at the Congress provided a congenial venue for planned and informal meetings

The colourful display and flags in the Booth attracted not only PARE delegates but also health professionals and clinicians from all over the world who were interested in hearing about the activities of the PARE community. Our member organisations shared leaflets, brochures and other materials and had the chance to communicate their activities directly to a broad international audience.

Thanks to the wonderful job done by our hard working team - Jolanta Grygielska, Codruta Zabalán, Lembe Kullamaa, Maria Batziou and our French MCI colleague Thibaut, the PARE booth was described as one of the most successful stands at the Congress.

Maria Batziou said "The location of the PARE Booth this year exceeded our expectations - we were at the centre of everything happening in the EULAR village and were able to engage in a lively way with our audience. I would like to thank the Booth team for their devotion, good humour and hard work that resulted in successful promotion of the "Vision 2043" competition, and made the booth such a warm and welcoming venue."

Health Professionals in Rheumatology at the Congress

by Sue Oliver, Chair EULAR Health Professionals in Rheumatology Standing Committee



Sue Oliver (left) and Christina Opava, Vice President representing Health Professionals in Rheumatology, at their stand at the Congress

The stands at this year's Congress in Paris were well placed, so the Health Professionals and PARE were reasonably close to each other. You would hardly believe it!! We were both so very busy and didn't get much of a chance to enjoy a cup of coffee together. We had a lot of interest from potential new member countries as I am sure PARE did too. Being busy is a measure of our joint success!

Fortunately for us we have plenty of time to keep in touch and share good ideas and approaches. Our joint sessions were well received and popular. The high quality of the presentations on subjects as varied as food as therapy, facilitating a normal life, and patient education ensured each pillar of the EULAR community continued to learn from the others.

We look forward to continuing our close collaborations for the future and of course Rome 2015!



EULAR Congress Paris



PARE's First Guided Poster Tour



What the PARE delegates said about the Congress

"I met some very interesting people. It was a real chance for me to learn a lot more about autoimmunity and myself/self-management, comorbidities etc. I have actually come home feeling more inspired than I've done for many years which is wonderful!"

"I appreciated the session "Food as therapy". And Marinka - the Stene Prize winner - really was fantastic when she read her abstract."

"I always thought that a lot of work was dedicated to produce a poster and then few would notice it and understand it. So this year one could take interest in the project as it was explained well and questions could be asked."

"Biosimilars is a hot topic and I have acquired some good information about it."

"Presenting our work from the national league: it is so nice to see we are growing, thanks to all we have learned at PARE and EULAR"

The perfect recipe for success

by Codruta Zabalan, Vice President, Romanian League Against Rheumatism



I have learnt the perfect recipe for preparing the PARE programme at the EULAR Congress:

Ingredients: dedicated people, like the EULAR Secretariat, Congress task force members and PARE Booth staff, liaison people from PARE national organisations, brilliant speakers and presenters;

Preparation: Blend and brainstorm all these together and come up with the best mixture of sessions and abstracts, for example: healthy ageing, travelling with RMDs, patient education, peer support in chronic diseases, non-pharmacological therapies, political campaigning, What's New, poster tours, smart decision making, highlights of the scientific and health professional sessions;

For special flavour: season everything with third party meetings, the Stene Prize award, the first PARE abstract award, Patient Research Partner networking, and a very welcoming PARE Booth;

Result: this Congress was a uniquely delicious concoction, novel and useful. By using these ingredients, patients, health professionals and rheumatologists produced an exciting and comprehensive programme (in line with all 7 Objectives in the EULAR Strategy 2017) with full audience participation from all three pillars of EULAR.

So I went home inspired, with clear values in my mind, ready to practice mindfulness in order to better cope with my rheumatic and musculoskeletal disease (RMD), to improve my diet, to sunbathe a little for my vitamin D, ready to organise self-assessment and self-management workshops in my national organisation, aware of my EU rights when travelling, ready to start collaborative projects at national and European levels, to advocate for patient reported outcomes (PROs) to be used in research and in clinical practice, and ready to take an active part of shared decision making in my treatment. **The perfect recipe for success!**





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