

eular

SPECIAL ISSUE

July 2016

e - BREAKTHROUGH

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

17th ANNUAL EUROPEAN CONGRESS OF RHEUMATOLOGY 8 - 11 JUNE 2016 LONDON



Thank you London
y ¡os esperamos en Madrid!



Dear members of the PARE community and PARE friends,

Almost 14,000 delegates from more than 100 countries in Europe and around the world attended the 17th Annual European Congress of Rheumatology from 8 - 11 June in London. Scientific researchers, clinicians, health professionals, physicians and people with rheumatic and musculo-skeletal diseases (RMDs) came together to learn about and discuss the development and progress in the treatment of RMDs.

At the Opening Ceremony, the President of EULAR, Prof. Gerd R. Burmester, and the EULAR Vice-President representing PARE, Marios Kouloumas, awarded the Edgar Stene Prize to Simon Stones, a 22-year-old student, for his essay on the topic "Living with a rheumatic or musculoskeletal disease: How I take action to live life to the full" (see photo below). In his essay Simon Stones described his struggles with an RMD and medications since 3 years of age and his will to succeed in his education, in spite of his illness and absences.



Nele Caeyers (Belgium) new Chair-elect Standing Committee of PARE

Wendy Olsder, another talented Young PARE member, received the award for the best PARE abstract (see photo below). Diana Skingle, past Chair of the Standing Committee of PARE, received EULAR honorary membership for her dedication and inspirational work for PARE. In the General Assembly, the appointment of Nele Caeyers as the new PARE Chair-elect was approved: welcome Nele!

The PARE programme offered excellent scientific and health professional speakers, broadening perspectives, and representatives from our member organisations focused on the realities of living with an RMD. I would like to thank everyone who made this informative and inspiring programme a success and those who worked hard at the PARE Booth, the ideal venue for information and establishing contacts.

I hope that the London Congress inspired and motivated you personally, and will support the future work in your organisation.

I look forward to seeing you in Madrid in 2017.

Dieter Wiek
Chairman, Standing Committee of PARE

Dates for your diary:



EULAR CONGRESS
14-17 JUNE
2017
MADRID



Simon Stones (United Kingdom) receiving the 2016 Edgar Stene Essay prize from Marios Kouloumas, EULAR Vice President representing PARE, together with Prof. Gerd R. Burmester, President of EULAR

PARE AWARD WINNERS 2016



Diana Skingle being awarded Honorary Membership of EULAR by the President of EULAR



Wendy Olsder (The Netherlands) receiving an award for the best PARE abstract from Marios Kouloumas, EULAR Vice President representing PARE, together with Prof. Gerd R. Burmester, President of EULAR

Highlights from the Health Professionals

by Prof. Christina H. Opava, Vice President Health Professionals in Rheumatology



Åsa Revenäs (Sweden) presenting in the session "Co-designing a mobile internet service for self-management of physical activity in rheumatoid arthritis"

The London Congress was a huge success for health professionals and I am very impressed by the knowledge shared by my fellow clinicians and researchers as well as by their presentation skills.

Some personal highlights come to my mind when trying to summarize, in a few sentences, what I brought back with me from London. An interesting session on how to co-design products and services by involving stakeholders from the start provided me with examples and tools to use within an important area that is not so easy for health professionals to grasp. Second, the importance of tailoring interventions to individual patients' needs, by e.g. cultural adaptation or by taking, not only patients' RMD into account, but also other diseases such as diabetes, cardiovascular disease or obesity was raised by several speakers. This is important since cultural bias and comorbidity often represent barriers to adequate care and rehabilitation, e.g. prescription of exercise. Third, physiotherapist Paul Kirwan from Ireland presented convincing data on how physiotherapists, using simple tools, can accurately distinguish patients with inflammatory disease from those with other RMDs, an illustrative example of how health professionals can contribute to the all-important early diagnosis and treatment.

Last, but not least it was my great honour and pleasure to convey the EULAR Meritorious Service Award to Dr Jackie Hill, rheumatology nurse specialist from Leeds, United Kingdom. She is the first health professional ever to receive this award, which is very well deserved and we are all proud of her accomplishments.



Dr Jackie Hill receiving the EULAR Meritorious Service Award from Prof. Christina H. Opava, together with Prof. Gerd R. Burmester, President of EULAR

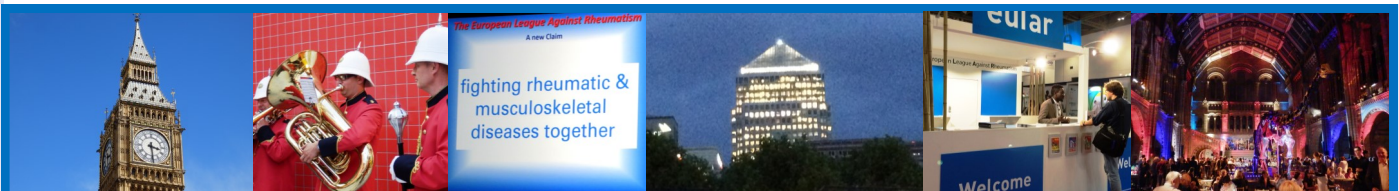
Taking Action at the PARE Booth



Once again the PARE Booth in the EULAR Village was the buzzing hub for PARE delegates and a great source of information for everyone. National organisations of PARE had the opportunity to display their own materials at the Booth and share their activities with an international audience.

Many health professionals, clinicians, patient representatives and other visitors had the chance to learn about the new World Arthritis Day (WAD) campaign "The Future In Your Hands". Thank you to everyone who promised to take action or who shared on-site their personal story of how they live their life to the fullest. If you haven't already done so, please share your story **by 29 July** on our website www.worldarthritisday.org – then you will have a chance to be chosen for inclusion in our WAD Montage Video 2016!

Special thanks also to the PARE Booth team: Eniola Asaolu, who worked hard with exceptional dedication and great enthusiasm; and our volunteers Claudine Goyens, Jolanta Grygielska and Elsa Mateus who were outstanding in their support. A highlight at the Booth this year was having Portuguese author Margarida Fonseca Santos handing out personally signed copies of her book "From zero to ten", a story about living with chronic pain. Margarida, who is a member of the Portuguese League against Rheumatism (LPCDR), also gave an inspirational talk about the power of the mind in one of the PARE sessions.



EULAR Congress London

Congress Report

by EULAR PARE Congress Task Force*



*B Combe and A Bosworth (seated) chaired **Optimizing treatment and patient care through precision medicine: a threat or an opportunity for patients and patients organisations?** with contributions from (left to right) B Kirkham, GR Burmester, B Glinthborg, J van Rompay and Y van Eijk-Hustings*

In June 2016, the prestigious EULAR Congress was once again hosted by the vibrant city of London. It lived up to all our expectations – the Congress offered an inspiring programme to its delegates, with the latest findings in the field of rheumatic and musculo-skeletal diseases (RMDs).

The wide-ranging PARE programme offered a variety of sessions, attended by health professionals,

clinicians and patient representatives. Some of the sessions were so popular that they were over-subscribed. In addition to those pictured, PARE sessions included talks featuring patient organisations in action, new approaches to managing pain, how e-health and m-health solutions can improve healthcare provision, and patient empowerment. An inspiring example in this latter session was the presentation by Simon Stones, the Edgar Stene Prize Winner 2016, and a very active member of Young PARE. Young PARE had high visibility at the Congress and organised a session to discuss solutions that enable young people to become involved in their own health care decisions.

The Abstract Session was the highlight for many delegates as sharing best practice is of such value for everyone. The latest advances in the treatment and management of systemic sclerosis were revealed in the 'What's New' session, which also featured a fascinating talk on the relationship between body and mind in fibromyalgia. PARE also ran two Poster Tours.

Ideally located next to the PARE Booth, these were a real feature in the overall programme, and were greatly enjoyed by the attendees.



The PARE Abstract session chaired by K Betteridge and J Grygielska (seated left and right) and featured (left to right) K Mace, Z Paskins, C Koehn, E Kritza, WR Nowell, N Lopuhaä, N Caeyers (and K Blidberg not pictured)

“The Congress Task Force, which plans the PARE Programme, works very hard all year long to provide interesting and inspirational content for our sessions. But it is our speakers, the abstract and poster presenters and you, as a lively and interested audience, who bring these sessions to life. We would like to thank all those who actively contributed to the 2016 PARE programme.

It is in the end your 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 2016 PARE programme planning team.

There is never enough time for every 'hot topic' to be featured during the busy Congress days. Luckily there is the next Congress to address them! The 2017 PARE programme is already being compiled and Madrid is looking forward to welcoming you all again next year!

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



There is more than drugs, a joint session between PARE and Health Professionals, chaired by Y van Eijk-Hustings and J Clausen (seated left and right) with session convenor D Wiek (far left) and presenters (left to right) C Schubert, K Turid, E van Giesen, K Pfeifer (and E Löfberg not pictured)

A message from Arthritis and Musculoskeletal Alliance (ARMA)

Dear friends of PARE

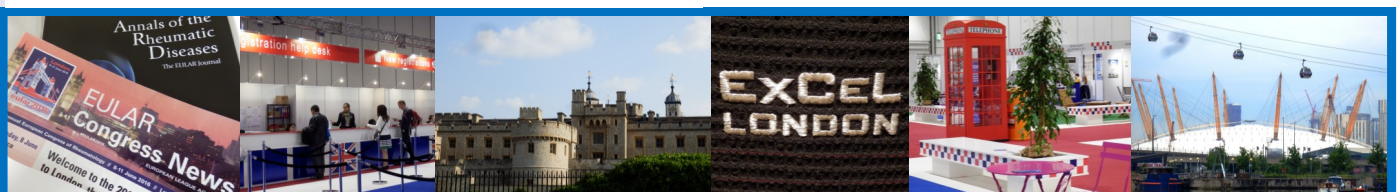
We were delighted to welcome you to the 2016 EULAR Congress in London.



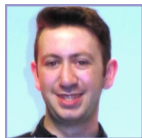
With the Global Burden of Disease data showing that musculoskeletal (MSK) disorders are the leading cause of years lived with disability, there has never been a greater urgency and better opportunity to improve the quality of life for all those living with Rheumatic and Musculoskeletal conditions.

ARMA's mission is to make MSK a priority in policy and practice in the UK and the Congress offered an unrivalled platform to collaborate and share knowledge and ideas to help make this a reality.

Professor Anthony Woolf, Chair ARMA



EULAR Congress London



Collaboration is the key to success

by Simon Stones, Member of EULAR Young PARE

Nearly 14,000 individuals with personal and professional interest in rheumatic and musculoskeletal diseases (RMDs) came together in London for the 2016 EULAR Annual European Congress of Rheumatology. It was evident that patients, patient organisations, health professionals and industry are increasingly working together to advance the care, treatment and quality of life of people living with RMDs, not just in Europe, but around the world.

This was my second attendance at the EULAR Congress, after attending for the first time in 2015. The energy and enthusiasm of delegates was electric! The majority of my time was spent with the PARE community, of which I am truly honoured to be a part. It was a busy few days, as I attended various PARE sessions, poster tours and networking opportunities. There was a real emphasis on the need for person-centric initiatives, involving patients, carers, health professionals and industry as equal partners. We also heard how innovative technologies will become a growing part of the day-to-day management of long-term health conditions and communication with healthcare teams.

There were many inspirational activities and stories from people across the world, as we learned how to better support people with RMDs. In addition, I was pleased to see delegates using social media to disseminate findings and discussions, enabling those

unable to attend in person to learn from the EULAR Congress.

Aside from the high quality programmes, I was delighted to see such a huge emphasis on involving patients in the Congress, and in particular, young people with RMDs. I am very much looking forward to EULAR 2017, and watching the Congress grow from strength to strength as we continue to work together for people living with RMDs.

Feedback from PARE delegates

"The people helping and supporting the Congress - in the exhibition, at the booth, in the sessions - were extremely friendly and helpful; I have never felt so welcome at a Congress before!"

"I think the PARE Poster Tour is an excellent idea. It is very good opportunity for patient organisations to introduce other people to their work, activities, etc

"Exceeded my expectations - for learning, networking, and more!"

"Presentations of much higher quality than previous years. Good session topics with speakers nicely complementing each other."





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



Follow EULAR and World Arthritis Day on Facebook and Twitter

EULAR Secretariat

Maria Batziou, Birte Glüsing and Florian Klett
Seestrasse 240, 8802 Kilchberg, Switzerland

Tel: +49 (0)228 9621283 and
+41 (0) 44 716 3035

Fax: +41 (0) 44716 3039

Email: Maria.Batziou@eular.org

Birte.Gluesing@eular.org Florian.Klett@eular.org

Website: www.eular.org

e - BREAKTHROUGH

EULAR Vice President

Marios Kouloumas

PARE Standing Committee

Chairperson

Dieter Wiek

EULAR Executive Secretariat

Maria Batziou

Birte Glüsing

Florian Klett

EULAR EU Office Brussels

Sören Haar

Federico Torres

Newsletter Editor and Co-ordinator

Diana Skingle

Publisher

EULAR Standing Committee of
People with Arthritis/Rheumatism
in Europe

Editorial Board

Codruta Filip

Birte Glüsing

Ingrid Pöldemaa

Petra Bednarova

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