Dear PARE friends,

Don’t Delay, Connect Today: that is what we did during four inspiring days in Amsterdam, The Netherlands. The Annual European Congress of Rheumatology, from 13 to 16 June 2018, was once again an amazing event where scientists, clinicians, health professionals and people with rheumatic and musculoskeletal diseases (RMDs) joined forces.

During the Opening Ceremony, EULAR President Prof. Johannes W.J. Bijlsma, President-elect Prof. Iain McInnes and EULAR Vice-President representing PARE Dieter Wiek emphasized the importance of collaboration between the EULAR pillars. In the new strategy plan for 2018-2023 there will be plenty of opportunities to make sure the voice of people with RMDs is heard.

The annual EULAR Congress will remain an important source of knowledge and networking for the PARE community in the coming years. The edition of 2018 has once again proved that our programme attracts a broad range of people. Interesting sessions often led to full rooms with no empty seats left. Both poster presentations (Thursday and Friday) were well attended and of high quality. In the EULAR Village, there were plenty of opportunities to get to know each other, and even have a wonderful massage at the PARE booth!

Congratulations to Magdalena Misuno from Poland, who won this year’s Stene Prize, and to Simone Engel from the Swiss League Against Rheumatism for winning the Best Abstract Award.

A big thank you also to Marios Kouloumas, who has said goodbye as past Vice-President representing PARE. This edition of e-Breakthrough would not be long enough to honour him!

EULAR 2018 could not have been successful without the help of many people and excellent presenters. Thank you all! We will meet again in Madrid next year. Preparations have already started to make sure we can present you the best programme ever in the Spanish capital city. See you next year!

Nele Caeyers, Chair, Standing Committee of PARE
Seeing the large number of enthusiastic health professionals in rheumatology (HPRs) involved in high quality scientific discussions, and in networking, was my main highlight of this year’s EULAR Congress. On reflection, I am even more convinced that PARE and HPRs should work together more closely in the future – both on an individual basis and at an organisational level. This will drive the future of rheumatology care in Europe!

What can health professionals offer to patients with rheumatic and musculoskeletal diseases (RMDs)? Examples include early referral to the right specialists and timely treatment, including, specifically, of osteoarthritis. Furthermore, HPRs support people with RMDs in their workplace through various different methods, advice and interventions. Productivity and paid work are essential activities of daily living and constitute a fundamental right of humans.

Prof. Dr. Tanja Stamm on behalf of Health Professionals in Rheumatology

The EMerging EULAR NETwork (EMEUNET) is increasingly engaged within EULAR activities including the Annual Congress which represents ‘THE’ scientific event to get together, learn and network. With almost 2000 members, our dynamic community of young individuals working in the field of rheumatology has been prominently involved in the scientific content of the congress with presentations on various research topics and participation in many other EULAR initiatives around the congress. We have welcomed colleagues from outside Europe, (USA, Japan and South America to cite a few), building connections to develop professional collaborations. EMEUNET is increasingly proving to be a powerful and influential platform for fostering new and long-term collaborative endeavours with the ultimate goal of promoting high quality education and research for the benefit of people with RMDs.

Alessia Alunno, Alexandre Sepriano and Elena Nikiphorou on behalf of EMEUNET

The 2018 EULAR Annual European Congress of Rheumatology closed just a few weeks ago and we are still catching our breath after well-attended PARE sessions, poster presentations and tours, evening receptions, and networking.

Our Young PARE community continues to grow thanks to fresh insights that present new dimensions in co-operation, expertise and best-practice sharing. We value the opportunities provided by EULAR and the EULAR Standing Committee of PARE. This exciting partnership delivered a unique Young PARE session, resulting in ever greater attendance and interest in our sessions from people with rheumatic and musculoskeletal diseases (RMDs), and health professionals in rheumatology, from across the globe.

We are looking forward to further co-operation and knowledge exchange that has huge scientific reach and true potential to improve the lives of young patients with RMDs.

Petra Balážová on behalf of Young PARE
From 13-16 June 2018 beautiful Amsterdam was host to another vibrant and inspirational EULAR Congress offering a packed programme for the more than 14,500 delegates who absorbed and shared the latest research findings in the field of rheumatic and musculoskeletal diseases (RMDs). Launched at the EULAR Congress 2017 in Madrid, the exciting EULAR campaign “Don’t Delay, Connect Today”, which raises awareness around the importance of early diagnosis and treatment, looked back at a very successful year. Numerous events at national level took place all over Europe. If you missed the video highlights in the EULAR Village at the PARE Booth, visit our campaign website and be inspired by action in the Outer Hebrides in Scotland, a mobile clinic driving through Cyprus, a high level policy event in Belgium and many more.

The PARE programme offered a variety of sessions attended by health professionals, clinicians and patient representatives with some of the sessions on topics like e-health for better care, and patient involvement in research, being very popular and overcrowded. In addition to those sessions, PARE addressed: the important topics of an inclusive school environment for young people with RMDs; challenges for patient organisations in the 21st century; innovative treatments; latest advances in treatment for juvenile idiopathic arthritis (JIA) and osteoarthritis; and work and rehabilitation. Plus there was a workshop discussing the important hot topic “Is there a diet for people with RMDs?” Despite the early Saturday morning timing, more than 50 delegates attended the workshop to learn about the latest evidence in the field, what patient organisations can offer patients, and how they can address the many questions concerning nutrition.

“EULAR PARE Congress Task Force would like to thank all those who actively contributed to the 2018 PARE programme and those who joined us at the congress. The quality of the programme this year was again extremely high and we were very satisfied with the great contributions provided by the speakers, and the abstract and poster presenters. It is, in the end, your activities and knowledge that make the congress such a success and so special each year” said Dieter Wiek, EULAR Vice President, representing PARE and leader of the EULAR PARE Congress Task Force.

There is never enough time for every hot topic to be featured during the busy congress days! Luckily there is the EULAR Congress 2019 to address them! The 2019 PARE programme is already being compiled and Madrid is looking forward to welcoming you all again next year!

* Marios Kouloumas, Dieter Wiek, Nele Caeyers and Elsa Mateus
The PARE Booth

This year the PARE Booth at the EULAR Congress 2018 was the place to be, not only for people with rheumatic and musculoskeletal diseases (RMDs) but also for the scientific and health professional attendees. The booth was conveniently located in the EULAR Village, in the heart of the EULAR campus, where a wide variety of activities and organisations were featured.

On each of the 4 days of the congress we offered a massage to people who visited the PARE Booth. And it was really refreshing to have a massage during the break between sessions and meetings. A wide variety of people from across the world (e.g. Japan, Indonesia, United States and Puerto Rico) came to the booth to find out information about PARE activities, and to meet PARE representatives.

The PARE Booth was also a meeting point for the many members of patient organisations who attended the congress, giving everyone a great opportunity to exchange results of on-going activities and to discuss plans for future projects. The Stene Prize 2018 booklet was very popular.

Also the booth screened inspirational videos from the “Don’t Delay, Connect Today” campaign that attracted lots of public attention. An informal survey carried out at the booth showed that, no matter where people live, the biggest obstacle to receiving early diagnosis for RMDs is late referral from general practitioners.

The hard work of EULAR PARE and national member organisations, and great support from the wonderful team of volunteers led by Claudine Goyens, resulted in the PARE Booth being a real showcase of PARE activities and programmes, and a very popular meeting point.

My 14th EULAR Congress by Marios Kouloumas

Berlin, Germany 2004, the Annual European Congress of Rheumatology, was the first congress that I attended as a patient representative. It was difficult to orientate myself in a clearly scientific event, even while recognising the meaning and reasons for my participation. But in general my excitement was based on the fact that by my being there it was acknowledged that patients are part of this European community that discusses, and works towards improving, the quality of life of the millions of people with rheumatic and musculoskeletal diseases (RMDs).

Of course, in those early years, the patients’ presence may have been small and perhaps unnoticeable amongst the rest of the representatives. There were far fewer interactions and, in many cases, neither the needs of patients were taken into account, nor were they integrated with the organisation of the congress.

However, the Annual European Congress of Rheumatology that has been organised by EULAR every year since 2000 has now managed to evolve and is considered to be one of the most important scientific congresses and is a must-attend event for everyone interested in any aspect of rheumatology. Apart from the presentation of the latest scientific updates about prevention, treatment and rehabilitation of RMDs, the congress provides an extensive forum for meeting and interaction between doctors, researchers, health professionals as well as patients, and anyone else involved in rheumatology. This is what makes it so successful and unique around the globe.

Patients today are an equal part of EULAR and participate fully with the other pillars of EULAR in organising the congress. With the wide support and information network of patients, PARE are now themselves able to organise an interesting and high quality programme that reflects the latest developments in all sectors of the management of RMDs. Personally, and I think it is the same for the most of you, it is with great satisfaction that I participated in the 2018 EULAR Congress: we have come a long way!
As in previous years, the two PARE poster tours at the EULAR Congress illustrated some really great themes and events from the patients’ point of view. The 17 posters on display attracted large audiences and showcased national achievements, projects and research. A wide range of topics were featured including:

- raising awareness of public transportation challenges by the Swedish national organisation for young rheumatics. “I was amazed and so happy to see the stickers on my way through the city of Stockholm after we launched the campaign” said Kim Nordlund;

- the importance of physical exercise for people with rheumatic and musculoskeletal diseases (RMDs) featuring Nordic walking in a World Arthritis Day campaign in Slovakia. “I do it now, and I love it. It is amazing, and I cannot promote it enough” said Petra Balážová;

- natural healing at the therapeutic treatment centres in Cyprus presented by Androulla Phoka Charalambous from the Cyprus League Against Rheumatism (CYPLAR); and

- supporting young people with RMDs in managing issues around relationships, pregnancy and sexuality by Wendy Olsder from Youth-R-Well.com (The Netherlands) who commented “We think there are more people who have these issues so we were thinking about organizing [the event] again in one or maybe two years depending on funding”.

- Well done everyone!

Feedback from PARE delegates

“I liked the setting of the room, the possibility to watch it from the outside through TV”

“I enjoyed presentations about inclusive school environment for young people with RMDs”

“Stene Prize Booklet was the most popular material provided at the PARE Booth. There were so many possibilities to get information. Thank you!”

“Leaving Amsterdam today after my first congress, #EULAR2018 was something special, thank you for the opportunity to speak & thank you for listening (actively)”

“The joint sessions HPT/PARE and PARE/Clinical were of great interest”

“The most happy place at #EULAR2018: the PARE booth!”

“Very well organized event. Excellent opportunities for networking”

“Very interesting topics to read from the posters and a lot of great work done by the persons behind them.”

“It was easy to move in the conference area enabling me to attend more sessions”
The European League Against Rheumatism (EULAR) is the organisation which represents people with rheumatic and musculoskeletal diseases (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

The Standing Committee of PARE would like to thank all those who have contributed to this newsletter.

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