Dear PARE friends,

It was really a good ‘Time2Work’ around some of the main issues concerning people with rheumatic and musculoskeletal diseases (RMDs) at the Annual European Congress of Rheumatology in Madrid from 12-15 June 2019, this year jointly organised with the Paediatric Rheumatology European Society (PReS).

We can hardly expect to summarize such an event in a few words! The EULAR Congress is indeed a unique experience: not only by its overwhelming magnitude, but mostly for providing simultaneously a very special environment for people with RMDs and their representatives, both within our own community and in a broader sense.

One of the special occasions was, of course, the Opening Ceremony, with the award of the Stene Prize to the Romanian Ovidiu Constantinescu for his essay “An interview with a Straight Face”, and the award for the Best PARE Abstract – “Geocaching as an encouragement for being active” – to Tinja Saarela, from the Finnish Rheumatism Association.* However, one of the highlights was surely the Meritorious Service Award acknowledging the contribution of Marios Kouloumas over the years to PARE, EULAR and to our community.

As for the PARE programme of 2019, we are proud to say that our room was often full of a broad range of people interested in our sessions. Beside the joint session with the Health Professionals in Rheumatology (HPRs), we had also a joint session with PReS. In addition, we held a workshop and introduced new session formats - a roundtable and an e-Poster station, all very successful, with plenty of opportunities for interaction.

A huge THANK YOU to all who were involved in EULAR 2019 and contributed to its success! But please don't forget that your active participation and inputs always play a key role in these learning and networking opportunities! Therefore, we hope to meet you next year in Frankfurt! So, it’s Time2Work for it!

Elsa Mateus, Chair, Standing Committee of PARE

* Available on the EULAR website, and in EULAR’s Abstract Archives, respectively.
Another successful EULAR Annual European Congress of Rheumatology took place in "caliente" Madrid, with several career-advancing opportunities for Health Professionals in Rheumatology (HPR) to embrace. As usual, a huge number of high quality scientific and clinically-meaningful presentations served as the basis of discussions and networking, this year together with paediatric HPRs.

HPRs very much welcome varied ways of engaging in active learning experiences, so more interactive session formats were tested, promoting increased debate among speakers and audiences – even introducing voting. It was also a great opportunity to share joint sessions with our PARE friends.

The congress provided an excellent opportunity for meaningful networking and meetings before and after the official programme. The EULAR Congress is increasingly becoming a place for international partners to discuss their ideas and projects in person. Ideas spark ideas at EULAR!

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

ENCA success at EULAR 2019 in Madrid

As president of the European Network for Children with Arthritis (ENCA) I am really proud that we have made a huge step forward. We are becoming more and more important as our little patients and their parents share all their information with us. For the first time, we had our own booth at the EULAR Congress. We had opportunities for great networking. We plan to join some more working and research groups, and work even more closely with paediatric rheumatologists. The International JIA (juvenile idiopathic arthritis) camp 2020 is our next big project.

I am glad that EULAR has taken a look at all aspects of the disease: mental health is very important; fatigue also spoils the daily activities of our children. I am so glad that we, parents, who are 24/7 with our children, can be a part of EULAR/PReS/PARE. We can help!

Mirjam Kepic, Slovenia, ENCA president

ENCA and PReS Logo

The EMerging EULAR NETwork (EMEUNET) is increasingly engaged within EULAR activities including the Annual Congress which represents ‘THE‘ scientific event at which to get together, learn and network. With more than 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. This year’s congress was even more special with EMEUNET celebrating its 10th anniversary and promoting several activities around it including a memorable joint dinner with the EULAR family. In addition, we have welcomed colleagues from outside Europe, (USA, Asia and South America to cite a few), helping to build 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.

Alexandre Sepriano, Felice Rivellese and Alessia Alunno on behalf of EMEUNET

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Alexandre Sepriano, Felice Rivellese and Alessia Alunno on behalf of EMEUNET
The EULAR Congress 2019, 12-15 June in Madrid, offered an exciting and packed programme for more than 14,500 delegates who absorbed and shared the latest research findings in the field of rheumatic and musculoskeletal diseases (RMDs). The PARE programme saw some innovative approaches implemented for the first time such as the PARE e-poster station, which was a highlight for many delegates as well as the presenters of two packed poster tours. Also, the first roundtable session “Don’t panic – Discussion on Risk Perception” was a major success with delegates as well as speakers appreciating the additional time for a lively audience discussion. “As convenor of this session, I am extremely pleased that this new format was so successful. But of course the excellent range of speakers and moderators also put a lot of thought into planning the session and really embraced the new concept” said Nele Caeyers, Past Chair of the EULAR Standing Committee of PARE.

The EULAR campaign “Don’t Delay, Connect Today”, with its new focus Time2Work, was very visible in the EULAR village, and the PARE Booth showcased a video compilation of all the wonderful country activities to date. Delegates could pick up their campaign sticker, and learn more about the campaign and the importance of work for people with RMDs. The booth team did a short survey and asked delegates about their most important wish regarding their work – flexibility of working time and an understanding attitude by their employer were ranked highest, closely followed by adaption of the workplace. The PARE Workshop “#ConnectToday and tomorrow: The campaigning continues” showcased 6 best practice examples at national level and prompted an animated discussion and inspirational exchanges of experiences.

The varied PARE programme, attended by health professionals, clinicians and patient representatives, also offered sessions on the latest news on biological treatment, digital health care solutions, treatment other than drugs, breaking down the barriers of transition, and managing fatigue, sleep and pain. There were also presentations on the risk of multi-morbidities for young people with RMDs, and on the benefits of involving patients in health technology assessment. All the sessions easily filled the room, with many more delegates standing outside watching on screen.

“The EULAR PARE Congress Task Force would like to thank all those who actively contributed to the 2019 PARE programme and those who joined us at the congress. The quality of the programme this year was really exceptional, and we were extremely 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 2020 to address them! The 2020 PARE programme is already being compiled and Frankfurt is looking forward to welcoming you all again next year! *Dieter Wiek, Nele Caeyers and Elsa Mateus
The PARE Booth  

**by Polina Pchelnikova**

At the EULAR Congress 2019 the PARE Booth was located in the EULAR village. It was visited not only by people with rheumatic and musculoskeletal diseases (RMDs) but also by numerous other congress attendees, including rheumatologists, researchers and health professionals from all over the world.

The booth provided information about PARE activities and an opportunity to meet PARE representatives. Many people took away copies of the Edgar Stene Prize essay competition booklets. There was also great interest in the EULAR campaign “Don’t Delay, Connect Today” with videos of the campaign in various countries showing on a large screen. This year, people also had a chance to take part in a survey about the EULAR campaign “Time2work” and express their views and aspirations on the topic of access to work for people with RMDs – 246 took part so we should have some interesting data to analyse.

As always, the PARE Booth was a meeting point for many people with RMDs and there was a fun photo/picture box at the booth where delegates could take a souvenir photo to capture their many inspiring encounters at the congress. It was a great opportunity for everyone to exchange news, the results of national projects, and to discuss options for future plans together.

Thanks to the wonderful work done by our hard working team, led by volunteer Claudine Goyens, the booth was an outstanding success. Claudine said “It was a really exciting and attractive booth this year with lots of activities that allowed us to engage in a variety of ways with our audience. It is always a very hard few days bringing everything together but the end result is really worth it. Thank you team!”

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**My First EULAR Congress**  

**by Stacey Grealis**

Having been informed of the scale of the congress, I was offered tips and advice on how to navigate and best be prepared for the event. Frequently, I was asked ‘Was I overwhelmed?’ At first, I was – but not by the rows of exhibition/information stands, poster viewing areas, submission sessions across numerous halls and auditoriums, nor by the 14,000+ attendees.

In a past life, I worked in events management and would have been rushing, racing and troubleshooting in the lead up to an event like this. I was not prepared for the emotions of how this was once part of my life and how different it is now, living with rheumatoid arthritis. After the first day, I overcame these feelings and enjoyed being a congress attendee and the buzz across the IFEMA conference centre.

The vast amount of information all in one place is so impressive that you want to absorb it all. Like other first timers I suffered from ‘Fear of Missing Out’ on the first days – which session to go to? Thankfully, all sessions are recorded. For me, the EULAR Congress was a great opportunity to speak directly with professionals face-to-face. I was surprised how many academics, medical and healthcare professionals took the time simply to chat. It was great to share experiences and collaboratively come up with new ideas to address the challenges in our community.

It’s exciting to see the work that has been done by researchers from the EU and across the world. I was enthused by the level of interest from young professionals, and by seeing how they are tackling societal problems and coming up with innovative and cost-effective measures to help people with rheumatic and musculoskeletal diseases (RMDs). I was overjoyed to hear, at many different levels, the importance of the patient’s voice and that better informed patients make better decisions about managing their condition.

It was fantastic meeting up with friends whom I have got to know over the last year. The Congress Gala Dinner allowed for great networking. It was an evening of excellent company and Spanish cuisine.

EULAR Congress 2019 was an informative, educational and enjoyable experience and I am looking forward to next year’s congress in Frankfurt where I can catch up again with my EULAR family from around the world.
PARE e-Poster Tours
by Ovidiu Constantinescu

For the traditional two PARE poster tours, Madrid marked a technological leap forward. For the first time, the printed posters were replaced by digital ones.

20 e-posters were displayed on a huge TV screen allowing the people to sit comfortably and concentrate on the topics put forward and not worry about the distance between the posters. “This was done with me in mind: it is perfect for me” said Antonella Celano from her wheelchair. Added to that, the e-poster display was there for everybody to see clearly, not only for the three or four lucky ones closest to board, as was the case with the printed poster tours. It was a win-win situation because the presenters too were happy with the new technology. From the slightly apprehensive “Let’s see how it works first and talk later!” of the first person to go (Connie Ziegler - Denmark) to Serena Mingolla’s (Italy) “It’s super. With minor adjustments it may be perfect”, the e-poster system got the thumbs-up from everyone.

Both tours were quickly booked up and, because the presentations took place in a highly visible location in the exhibition hall, they attracted a lot of passers-by who stopped to watch. A wide range of outstanding projects and activities were featured in the posters, all relevant for people with rheumatic and musculoskeletal diseases. Discussions continued long after the tours had ended.

Congratulations to everyone who took part!

Feedback from PARE delegates

“This year was one of the best. Very good projects and speakers.”

“I liked the format, with very short speeches and more room for debate.”

“I loved it! The #ConnectToday workshop was excellent I got very good ideas, which we are going to implement in our country.”

“Very interesting roundtable format - short presentation, f2f discussion and Q&A in smaller groups.”

“This was my first experience at a EULAR Congress. I enjoyed it and learnt loads from all sessions that I attended as well as from the Poster Sessions.”

“The way delegates were involved everywhere was great. The quality of the sessions - so professional.”

“We had 3 staff at EULAR and so split sessions between us in order to cover as much as possible.”

“I really appreciated the “EULAR Family” mind-set, meaning that delegates were involved to a greater extent than in earlier years - seemed to be fully integrated and that is fantastic.”
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 on

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EULAR supports the Global Alliance for Musculoskeletal Health http://bjdonline.org

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