



Special Issue July 2017

e - Breakthrough

eular

fighting rheumatic & musculoskeletal diseases together

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



18th EULAR Annual European Congress of Rheumatology 14-17 June 2017 Madrid

Farewell Madrid!

Tot ziens in Amsterdam!



Dear members of the PARE community and PARE friends,

More than 14,000 people celebrated the 70th anniversary of EULAR during the Annual European Congress of Rheumatology from 14-17 June in Madrid. Scientists, clinicians, health professionals and people with rheumatic and musculoskeletal diseases (RMDs) learned about 70 years of rheumatology and the history of EULAR. It was great to see how much has changed by joining forces.

EULAR launched its campaign **“Don’t Delay, Connect Today”**, supported by all three pillars of the organisation. With a focus on early diagnosis, EULAR wants to raise awareness and to improve the quality of life for all people with RMDs. PARE members, health professional organisations and scientific societies will be encouraged to take action at national level.

“Don’t Delay, Connect Today”

A report on how the Spanish organisations successfully promoted the campaign in Madrid is on page 4.

During the Opening Ceremony, two PARE award winners were announced: Stefanie Hulst from

The Netherlands won the Edgar Stene Prize with her story on the importance of early diagnosis; and Karl Cattelaens from Germany received the award for the best PARE abstract.

“Inspiring talks and innovative projects”

The PARE programme was filled with inspiring talks and innovative projects from all over Europe. PARE delegates had plenty of opportunities to network and to enhance the work in their own countries. A big thank you to everyone who helped to develop a splendid programme, as well as to the people at the PARE booth who spread our message in the EULAR Village.

We enjoyed the 70th anniversary in hot Madrid! Let’s make the 71st birthday as remarkable as this one! See you in Amsterdam in 2018!

Nele Caeyers
Chair, Standing Committee of PARE

New appointments in EULAR



(Left to right)

Dieter Wiek, EULAR Vice President, representing PARE

Prof. Annamaria Iagnocco, Treasurer

Prof. Ruxandra Ionescu, General Secretary

Prof. Iain McInnes, President-elect



PARE Abstract Award

Winner **Karl Cattelaens (Germany)** together with **Marios Kouloumas, EULAR Vice President representing PARE (left)** and **Prof. Gerd R. Burmester, President of EULAR**



Edgar Stene Prize

Winner **Stefanie Hulst, (The Netherlands)** together with **Dieter Wiek, Chair of PARE (left)** and **Prof. Gerd R. Burmester, President of EULAR**

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70

anniversary
1947 - 2017

Around the EULAR Congress 2017

Health Professionals in Rheumatology

The EULAR Congress in Madrid was a great success for the enthusiastic and highly motivated Health Professionals in Rheumatology (HPRs) who were participating. HPRs celebrated their 30th anniversary at EULAR in Madrid 2017. Three of the HPR founders, of whom we are very proud, were invited and shared their experiences with the current and 'future' HPR leaders.

Professor Ulla Nordenskjöld, who did substantial work in research and clinical practice, received the Meritorious Service Award. Sessions, posters and poster tours were very well attended and a lot of new knowledge in research and clinical practice was discussed covering topics such as: wearables, transition, patient engagement, fibromyalgia and osteoporosis.



Two of the founder members of Health Professionals in Rheumatology Angelika Kruse-Jensen (left) and Vicky Stevenson



Winners of the EULAR Meritorious Service Award
Ulla Nordenskjöld (second from left) and Tore Kvien (second from right), together with (far left) Maurizio Cutolo, EULAR Past President, and Gerd R. Burmester, EULAR President

Furthermore, we met our international rheumatology friends and collaborators, including our American colleagues. We discussed future projects, grant proposals and clinical, educational and scientific collaborations within Europe.

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

EMEUNET



Elena Nikiphorou, Sofia Ramiro & Alessia Alunno on behalf of EMEUNET

Year after year EMEUNET's presence at EULAR is getting stronger and more influential. Our dynamic community of young individuals working in the field of rheumatology makes EMEUNET a powerful and influential platform for fostering new and long-term collaborative endeavours. Our EMEUNET members were prominently involved in the scientific content of the congress, presenting work and participating in key EULAR initiatives. We have welcomed a number of friends from Europe and also across the Atlantic and engaged in social and professional activities bringing people together and building strong friendships. We look forward to happy and exciting times ahead, yet again!

PARE Booth



Maria Batziou (left), EULAR Secretariat, and Carlos Torrigos

The PARE Booth at the EULAR Congress 2017 in Madrid was the hub of PARE activity during the congress.

PARE delegates and other congress visitors had the chance to learn about PARE activities and how to get involved in the EULAR campaign "Don't Delay, Connect Today". The updated www.worldarthritisday.org website was also launched successfully and was a valuable source of information and guidelines about rheumatic and musculoskeletal diseases (RMDs).

Our thanks go to everyone who contributed to the success of the PARE Booth, especially to our Spanish MCI colleague Carlos Torrigos whose hard work and enthusiasm attracted the visitors, and volunteer Claudine Goyens who calmly and kindly answered questions and helped everyone to find all the information they were seeking. A great team!



Claudine Goyens (right) and visitors to the PARE Booth in the EULAR Village



Congress Report by EULAR Congress Task Force*

The EULAR Congress 2017 was again hosted by the vibrant and beautiful city of Madrid. The packed event offered an inspiring programme of the latest findings in the field of rheumatic and musculoskeletal diseases (RMDs) for more than 14,000 delegates.

EULAR celebrated its 70th anniversary in 2017 and delegates were invited to recall all the exciting developments in treatment and care of RMDs that have taken place over the last seventy years, reflecting at the same time on the history of EULAR and the progress it has made over the same period.

The exciting EULAR campaign “Don’t Delay, Connect Today” was successfully launched at the Madrid Atocha train station prior to the congress (see page 4). The campaign was highlighted throughout the PARE programme and at the EULAR PARE booth. EULAR President Prof. Gerd R. Burmester and his colleagues shared latest knowledge on the importance of early diagnosis and treatment in RMDs. Information was also shared on how to support the campaign. We hope that many organisations will take inspiration from the brilliant Madrid launch and get involved!



Health equity and economy - a vital relationship chaired by P Pchelnikova (fourth from left) and E Mateus (fourth from right) and featured (left to right) A Bosworth, P Putrik, B Fautrel, N Betteridge, FJ Carreira Roca and M Kouloumas (session convenor)



Joint session Clinical/HPR/PARE: EULAR Campaign: Don’t Delay, Connect Today chaired by GR Burmester and A Bosworth (far right) and featured (left to right) LA Bennett, J Church, P Kirwan, SD Mallen and A Schwarting

The PARE programme offered a variety of sessions attended by health professionals, clinicians and patient representatives with some of the sessions being very popular and overcrowded. In addition to those pictured, PARE sessions addressed the important topics of co-morbidities, how to bring rheumatology research to the next

volunteers in their organisations. PARE poster tours were also arranged and, as in previous years, these were enjoyable and insightful, giving delegates the opportunity to present their successful national programmes and projects.



Barrier-free employment for young people with RMDs chaired by A Phoka (second from left) and A Alunno (fourth from left) featured (left to right) G O’Leary, L Kullamaa, J Anderson, M McAllister, P Putrik and M Kouloumas (session convenor)

level, the challenges of patient partnerships in research, the need for improvement of psychological support for people with RMDs, and heard the Edgar Stene Prize winner Stefanie Hulst from The Netherlands reading her powerful essay.

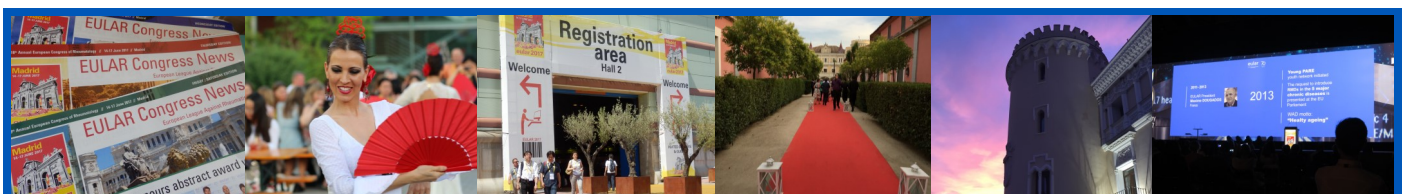
“The EULAR Congress Task Force works very hard all year to provide interesting and inspirational content for our PARE sessions. The quality of the programme this year was extremely high and we were very satisfied with the great contributions provided by the speakers, and the abstract and poster presenters. We would like to thank all those who actively contributed to the 2017 PARE programme and those who joined us at the congress. It is, in the end, your expertise and knowledge that make the congress such a success and so special each year”

Dieter Wiek

There is never enough time for every hot topic to be featured during the busy congress days! Luckily there is the EULAR Congress 2018 to address them! The 2018 PARE programme is already being compiled and Amsterdam is looking forward to welcoming you all again next year!

** Marios Kouloumas, Dieter Wiek, Nele Caeyers and Maarten de Wit*

For the first time PARE organised a workshop at the congress. Despite the early Saturday morning timing, more than 40 delegates attended to discuss how to attract, manage and keep





EULAR Campaign

by Victoria Romero Pazos

LIRE, the Spanish League against Rheumatism, member of EULAR since 1975, was honoured to organise, in collaboration with SER, the Spanish Society of Rheumatology, and OpenReuma, the launch of the EULAR campaign “Don't Delay, Connect Today” in Madrid's Atocha train station on 13 June 2017.

For us, one of the most important elements of this campaign was to have been able to co-ordinate, at national level, the three pillars of EULAR: people with rheumatic or musculoskeletal diseases (RMDs), rheumatologists and health professionals in rheumatology. We wanted to communicate the motto of the campaign by showing that we are indeed connected and working together with the same objective, which, in this particular case, is the well-being of people with RMDs and the need for early diagnosis and treatment. Each stakeholder has a part to play.



All ready to go - the Madrid launch team

We were at the main entrance hall of the station all day, with volunteers from each organisation handing out information to passers-by. Three professional actors, specializing in improvisation, caught the attention of the travellers, and interacted with them delivering the key messages of the campaign, whose adapted slogan was “No pierdas tu tren” (Don't miss your train) underlining that no time should be lost in taking action in important matters.



Maurizio Cutolo, EULAR Past President (left) joined by the President of the Spanish Society for Rheumatology (SER), Dr. José Luis Andreu Sanchez, and Victoria Romero Pazos, spokesperson for LIRE and EULAR liaison for the campaign launch

Various political representatives came to the station to visit the booth and to show their support, and also to get ideas of how they can help in their public role to improve the time to get a diagnosis or to access treatment. In Spain we have 17 autonomous regions with different healthcare systems and our campaign launch was therefore attended by regional and national politicians.

In summary, the atmosphere was that of an enthusiastic team, and



Hans Bijlsma, EULAR President-elect, and Maurizio Cutolo, EULAR Past President, supporting the campaign launch in Madrid

we had the feeling that we are building a long-term relationship. And all the passers-by and politicians responded very well to the campaign.

Message from Liga Reumatológica Española (LIRE)

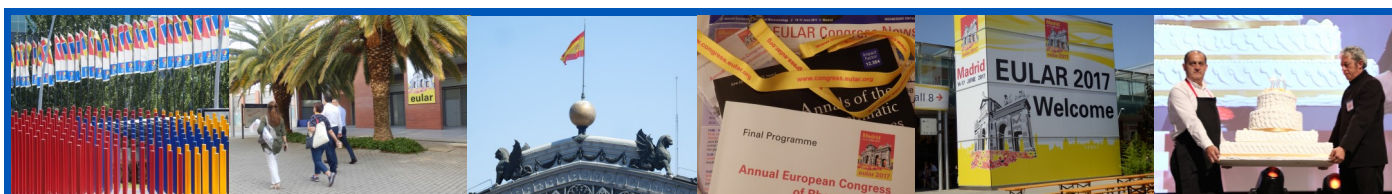
Dear friends of PARE,

It was a great pleasure to welcome you to Madrid and to the 2017 EULAR Congress.

We also had the honour to coordinate the launch of the new EULAR campaign "Don't Delay, Connect Today" working in tight collaboration with rheumatologists and other health professionals, giving us the chance to strengthen the relationship among the three pillars of EULAR.

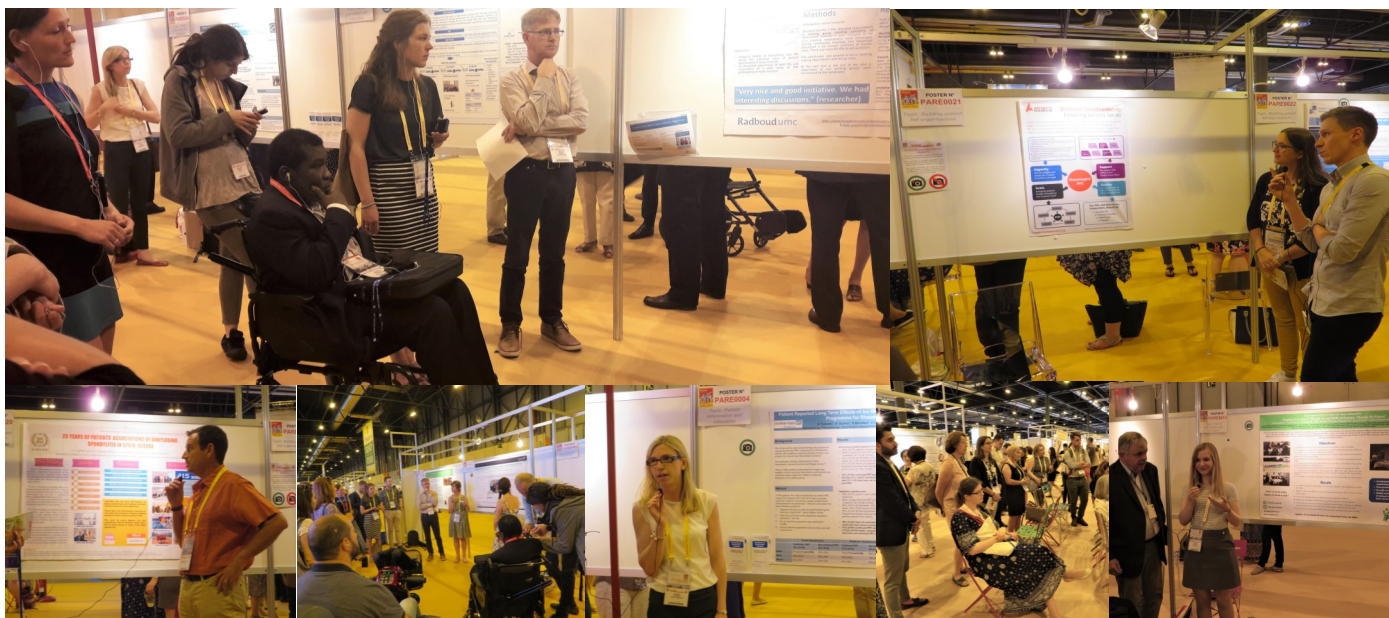
One of LIRE's most important aims is to provide a platform for the dialogue of all the stakeholders involved in improving the quality of life of people with an RMD, creating a place where patients are given their own strong voice as equals in decision making.

Benito Martos, President LIRE



PARE Poster Tours

Two PARE poster tours took place at the Congress. Twenty-two posters were on display. There were opportunities to showcase national achievements, projects and research. Topics ranged from patient involvement in research, transition, news from Young PARE, to powerful campaigns like "Behind the smile" from the UK. This year the number of PARE abstracts was the highest ever and the quality of the entries improves every year. Congratulations to all those chosen to present their posters!



Feedback from PARE delegates

"The session 'Barrier-free employment for young people with RMDs' was extremely interesting and opened up a good and productive discussion!"

"I particularly liked the presentations on 'Work' - as this is an issue that affects everyone with RMDs whatever their age."

"'Difficult to reach patient groups' - a pleasant surprise. I expected minor interest, but I was wrong. It was really interesting to learn what are the challenges for those people with RMDs from different ethnic backgrounds and what has been done to help them. The Swedish case study was an amazing example."

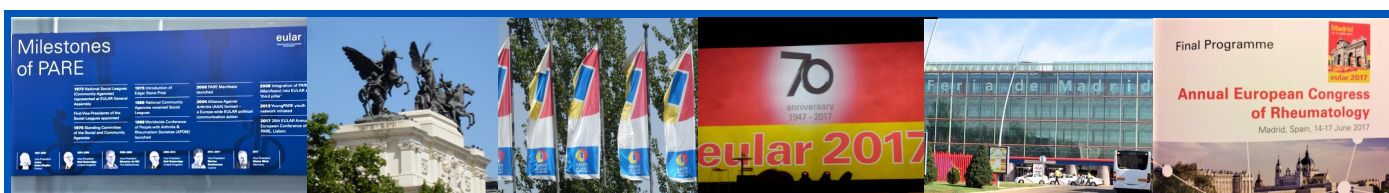
"My personal highlights were the joint sessions with health professionals - it's

great to bring people of different experiences together in a room."

"I participated in both poster tours and I am amazed how the PARE organisations work and that so many good projects were presented."

"Fantastic event - first time I had attended, we were made most welcome and were impressed by the wide range of sessions and events."

"The new workshop format brought a varied group of people from different backgrounds to have a place to share their ideas and learn from each other. It was also a relief for patients who had sat and been talked at for days - a really interactive idea that involved everyone."





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

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