

e - BREAKTHROUGH

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

eular

fighting rheumatic & musculoskeletal diseases together

70
anniversary
1947 - 2017

Inside this issue:

- Introducing EULAR
Executive Director
Dr Julia Rautenstrauch 2
- The EULAR School of
Rheumatology and
The PARE Classroom 3
- Chief Executive Officers
meet in Stockholm 4
- PARE partner in
EU project HarmonicSS 4
- What do patients think
about their care? 5
- Online self-management
in Ireland 5
- In memory of
Dora Papastavrou 6

Dates for your diary:

- **6 May:** World Ankylosing Spondylitis Day
- **10 May:** World Lupus Day
- **12 May:** Fibromyalgia Awareness Day
- **20 May:** World Auto-Immune Arthritis Day
- **14-17 June:** Annual European Congress of Rheumatology EULAR 2017, Madrid

Would you like to read about your national organisation's activities in one of the next issues?

Please send your article (300 words max and photographs) to birte.gluesing@eular.org

Looking to the future

by Dieter Wiek,
Chairperson of the EULAR Standing Committee of PARE



Dear PARE community and friends of PARE

Our EULAR PARE Annual Conference at the end of February in Lisbon was a tremendous success. It was great to experience the enthusiasm of about 120 delegates in workshops and networking. If you are interested in getting to know more about the conference, just go the EULAR website where the streamed programme and various sessions are available.

However, it was with great sadness that we received the news that Dora Papastravrou had passed away shortly afterwards. She was an enthusiastic participant at the Conference and in her work with Young PARE. We send our sincere condolences to her family and friends. (see page 6)

Now we are looking forward to the Annual European Congress of Rheumatology EULAR 2017 in Madrid. The PARE task force has put together a broad range of topics with high profile speakers. You will be

able to present your activities through oral abstracts and posters.

Due to retirement and new work challenges, there have been some changes to the EULAR staff. I'd like to thank Heinz Marchesi for all his collaboration and support. We are looking forward to working together with EULAR's new CEO Dr Julia Rautenstrauch, and with the other new staff members Dr Lydia Tchambaz and Ursula Aring (see page 2). Welcome to the EULAR family!

This is my last editorial for e-Breakthrough as Chair of the Standing Committee of PARE and I'll hand over to Nele Caeyers after the EULAR Congress in June. It has been a pleasure to be Chair; thanks for all your support and encouragement.

I hope to see and talk to you in Madrid or at one of our future PARE events.



EULAR 2017 Congress in Madrid

From 14 - 17 June the rheumatology world will focus on beautiful Madrid, the host city for the Annual European Congress of Rheumatology EULAR 2017. **Celebrate EULAR's 70th anniversary with us!** Scientists, health professionals and people with rheumatic and musculoskeletal diseases (RMDs), and their respective organisations, will gather for 4 days of intense discussions and networking, sharing the latest advances in the field of RMDs through lectures, workshops, abstracts, poster presentations and symposia.

This year EULAR received the highest ever number of abstracts; and so did PARE. "We are very satisfied with the abstract submissions of the PARE community - not only the high number but also the excellent quality" said Marios Kouloumas, EULAR Vice-President representing PARE. "The 2017 PARE Programme has many hot topics on its agenda. We will talk about psychological well-being, co-morbidities, employment for young people, health equity, the importance of early diagnosis, and access to health care. Our first workshop will look into how to manage volunteers."

Hasta pronto in Madrid - we hope to see many of you there!



Introducing EULAR Executive Director Dr Julia Rautenstrauch

Replacing Heinz Marchesi in March 2017, Dr Julia Rautenstrauch has joined EULAR as its new Executive Director. She shares her first impressions with e-Breakthrough:

My first weeks at EULAR have been extremely busy getting acquainted with all the different people and topics under the EULAR roof. I am very impressed by the unique, common spirit of the three pillars of EULAR and especially by the PARE contribution, which, from my point of view, is an outstanding characteristic and enables EULAR to perform extremely well, especially on the political stage. I don't know any other organisation where professionals and patients are acting jointly in such a close and efficient way. This very special attribute was one of the main drivers for my decision to choose EULAR as my new place of work. I am very proud to be a member of the EULAR family and will do my very best to support your work in order to achieve the best results.

I am also impressed by the variety of PARE activities and I hope that next year I will be able to attend the PARE conference; it seems to be the annual highlight, which builds up strong connections among the delegates and provides unforgettable memories. This year, I followed the event via the live stream video on the internet – this was an exciting, new experience and I learnt how PARE manages to involve people from all over the world without any barriers: Congratulations!

A few words regarding my professional background: I am a physician and a journalist and I have a longstanding connection to the field of rheumatology, first as a medical journalist, covering the American College of Rheumatology (ACR) and EULAR congresses, and later as press officer of the German Competence network for Rheumatology. Most recently, I was the General Secretary and Managing Director of the German Society for Rheumatology. And now I am looking forward to working with all of you!

Goodbye Heinz!

Heinz Marchesi was Executive Director of EULAR when PARE Manifesto merged with EULAR in 2008. Together with the PARE leadership he invested a lot of time, and was instrumental, in ensuring that the work of the patient organisations was embedded successfully within EULAR's existing structures and activities. Today, EULAR would not be complete without PARE as one of its three pillars, contributing actively to the strength and reputation of the organisation. PARE would like to thank Heinz Marchesi for the great support and vision he provided and wish him all the very best for the future!



Members of the EULAR Secretariat (left to right):
Patrizia Jud, Simone Luescher, Susanna Lieberherr, Heinz Marchesi,
Birte Glüsing, Gabriela Kluge, Florian Klett, Lydia Tchambaz,
Maria Batziou, Ursula Aring

Meet two new members of the EULAR Secretariat team

Dr Lydia Tchambaz (Deputy Executive Director):

"I joined EULAR in September 2016 and since then I have been extremely impressed by the passion and dedication of each single person I have meet across the organisation. The highlight during my first 6 months has been by far my attendance at the PARE Conference. It was a privileged moment for me to have the chance to get in contact with delegates of the PARE organisations and to learn more about our shared goals and missions. It is difficult to describe the magic but I can say that those days will always remain in my heart. My main task during the next months will be to develop further the School of Rheumatology and the EULAR campaign "Don't delay, connect today" together with the Campaign team, two wonderful projects which have already given me the opportunity to get to know wonderful people."

Ursula Aring (Communications Manager):

"I joined EULAR as Communications Manager on 1 December 2016. My role is to work with all areas of the organisation's network to achieve understanding, acceptance and active engagement regarding rheumatic and musculoskeletal diseases (RMDs) among all areas of society, from political and regulatory through to society at large. To achieve this, I am managing and developing communications channels including digital and social media. Prior to EULAR, I worked in business communications in the private industry sector. With a personal interest in design, I also have experience in fashion and lifestyle design projects. I look forward to working with and contributing to EULAR, its future and its people."



The EULAR School of Rheumatology

by Prof. Annamaria Iagnocco, Chairperson of the Standing Committee on Education and Training and Dr Lydia Tchambaz, EULAR Deputy Executive Director



Prof.
Annamaria
Iagnocco

The EULAR School of Rheumatology is the most recent and ambitious EULAR initiative that aims to combine all its educational offers, from live courses and online courses to books and webinars, under one single roof. It is an exciting, novel approach to EULAR education with the target of becoming the global leader in rheumatology education, accessible by all from everywhere in the world. Indeed, the vision

of the EULAR School of Rheumatology is to be the pre-eminent provider and facilitator of high-quality educational offerings for physicians, health professionals in rheumatology, and people with rheumatic and musculoskeletal diseases.

The School will host educational activities that have already been available for some time, such as the Knowledge Transfer Programme designed for patient organisations that wish to improve their skills by learning from the experience of other organisations in the EULAR network. However, new educational offerings, in different teaching forms with a variety of lengths, topics and composition, will also be developed, and year-round webinars will also be delivered.

In order to address the needs of the different target groups and individuals involved in the field of rheumatology, different classrooms have been created with the mission of identifying novel educational tools aligned with the spirit of the time and the current trends, like digitalisation and globalisation. Currently, there are seven classrooms composed of pre-eminent experts in the field of education in rheumatic diseases who are working for:

- PARE
- medical students, undergraduates
- trainees, residents, fellows in training
- teachers
- rheumatologists
- researchers
- Health Professionals in Rheumatology



Dr Lydia
Tchambaz

In particular, the PARE classroom faculty currently consists of five teachers involved in education from different countries, aiming to develop new educational content and to bring quality knowledge and information to people with rheumatic and musculoskeletal diseases all around the globe.

For more information please see the EULAR website.

The PARE Classroom

by Dieter Wiek, Chairperson of the Standing Committee of PARE

For PARE, the EULAR School of Rheumatology offers a great opportunity to spread EULAR's educational offerings to the PARE community in Europe, perhaps even world-wide as we see growing interest in our activities beyond Europe. As our first step we will focus on educational material for organisations, but later on we should also find ways how to support individuals who want to manage their life with a rheumatic and musculoskeletal disease (RMD).

What do we have already?

- Educational materials have been produced for PARE's Patient Research Partners project. The reference cards and explanatory brochure are available on EULAR's website for organisations that would like to learn how to involve people with RMDs in scientific projects.
- For patients, short lay versions of EULAR recommendations are available to help to promote self-management.
- Recorded sessions of EULAR PARE Annual Conferences, from 2015 onwards, are available on the EULAR website so that those who are interested can review and - if wished - learn from the sessions. For example, see "Self-management: What steps can organisations take to help?"

What will be developed and available soon?

The EULAR PARE Annual Conference in Lisbon in February held two fantastic workshops aimed at enhancing the skills of delegates. Resulting from these workshops, a guide that teaches "How to conduct media interviews" and a training manual that outlines "How to make a video" will be made available soon. Several videos made at the conference demonstrate the practical application of the skills learnt.

Currently, we are developing a course on how to implement the Patient Expert Programme. The aim of this course is to show organisations where patients can be useful as experts (e.g. for training medical students at universities, or nurses at educational institutions), and how patients should be selected and trained etc.

The future expansion of educational offerings in the PARE classroom certainly depends on our hard work and on financial resources. But we are on an inspiring path for improving the work of our member organisations.

Chief Executive Officers of EULAR PARE member organisations meet in Stockholm by EULAR Secretariat



CEOs attending the successful exchange meeting in Stockholm

Reumatikerförbundet hosted the EULAR PARE CEO Exchange Meeting from 2 - 3 February 2017 in Stockholm, Sweden. The annual EULAR meeting gathers the leaders of PARE organisations that have paid full-time CEO positions, and employ at least five paid staff members. "This platform is extremely useful as we CEOs all face similar challenges. I came home full of inspiration, and the outside perspective of the group helped me to find solutions to my national problems and to think out of the box." said Maria Ekroth, CEO of the Finnish Rheumatism Organisation.

Leif Salmonsson, CEO of Reumatikerförbundet, and his team, introduced the impressive work portfolio of their organisation. The work is managed by a highly professional team of 30 employees in their central Stockholm office. For 2016, the fundraising department raised an income of Euro 4.7 million, of which 72 % originated from legacies – a unique situation in Europe. A lot of this money is invested into research – the organisation is the biggest donor to rheumatology research in Sweden. In the Spring, Reumatikerförbundet will launch a new mobile app linked to an official national data hub. It can be used to book appointments with the doctor or physiotherapist, share records and data within the health care team, order deliveries from the pharmacy etc. The patient decides with whom to share their data and information.

While all these developments sound very exciting there are also challenges to face. The biggest one is the decrease in members. It was confirmed that this development is not unique to Sweden and that other countries face a similar situation. The PARE community needs to discuss this and find solutions.

The rest of the agenda featured the hot topic of access to treatment and health care. The group discussed and shared their worries about the situation around biosimilars where some countries still do not have registries, and treatment decisions are guided by financial priorities. Prof. Hans Bijlsma, EULAR President-elect, also shared information about the development of EULAR recommendations, and set the scene for a discussion about the latest developments in biosimilars. Finally, the EULAR EU Office in Brussels introduced the latest developments at EU level.



PARE partner in EU project HarmonicSS

by Elsa Mateus, EULAR PARE Coordinator for HarmonicSS



HarmonicSS is a Horizon 2020 research project entitled "HARMONization and integrative analysis of regional, national and international Cohorts on primary Sjögren's Syndrome (pSS) towards improved stratification, treatment and health policy making".

pSS is a disease where effective treatments are still lacking and where many novel and expensive targeted therapies are under investigation. Despite the high activity in the field, there is a high risk of sub-optimal results, largely because there are no common shared criteria to distinguish and select the patients (e.g. per type of auto-antibody positivity or duration of the disease). EULAR and the American College of Rheumatology have worked towards improving this and have developed novel classification criteria for pSS

(2013), and EULAR initiated the development of the Sjögren's Syndrome disease activity index – ESSDAI (2015).

Another reason for sub-optimal results is that patient databases are governed by a highly heterogeneous variety of medical and legal rules across Europe. Data is still collected in diverse databases across the different EU countries, making comparisons difficult. The HarmonicSS project aims to improve the databases and tools through international collaboration between researchers and other stakeholders, and is a crucial step for the study and diagnosis of pSS.

This is an exciting pilot for EULAR as it brings in the patient perspective via the EULAR Standing Committee of PARE. Together with the US Sjögren's Syndrome

Foundation - SSF (www.sjogrens.org) EULAR PARE will monitor, evaluate and advise on project outcomes in terms of impact to patients, and will disseminate developments and results.

The active involvement of EULAR PARE, as well as national patient associations, will ensure the patient focus in the project and will improve implementation of the results.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 739144, and from the Swiss State Secretariat for Education, Research and Innovation SERI under grant agreement 16.0210. It involves 35 partners from 15 countries, led by the University of Athens, Greece.



What do patients think about their care?

by Nele Caeyers, Spokeswoman, ReumaNet



In 2016, ReumaNet, the Flemish platform for rheumatic and musculoskeletal diseases (RMDs) patient organisations, set up a survey to learn what patients think about their care. Over 700 people participated.

People living with a chronic condition day-in day-out develop a certain expertise. This knowledge and expertise is not only useful for patient organisations, but is also valuable for health care providers, policy makers and the pharmaceutical industry.

The survey contained 40 online questions for people with an RMD and covered information, treatment, research, relations with rheumatologist, physiotherapist, general practitioner and pharmacist, communication between these care takers, and the role of patient organisations.

711 people completed the questionnaire. The majority had rheumatoid arthritis (48%), but also ankylosing spondylitis, psoriatic arthritis, juvenile idiopathic arthritis, connective tissue diseases, fibromyalgia, osteoarthritis and osteoporosis were represented. 48% considered themselves well informed about their condition but only 34% were well informed about their treatment and medication. Patients pointed out they want to talk about their future expectations during consultations, something which is hardly ever addressed today. A fear of side effects is the main reason not to take medication as prescribed (51%).

The question: 'How satisfied are you with your rheumatologist' received a score of 7/10. Not listening to the patient and not taking him/her seriously were the biggest concerns. Communication between rheumatologist and general practitioner (GP) scored a low 6/10 and shows the importance of a good multidisciplinary team. Spreading information among patients was said to be the biggest task for patient organisations (82%).

Conclusions: People with RMDs:

- Want more information on treatment and medication options
- Want more information on future disease development
- Are afraid of side effects of medication
- Are moderately satisfied with their rheumatologist and satisfied with their health professionals
- Want more communication between rheumatologist and GP
- Want to discuss expectations for the future during their consultations
- Believe patient organisations are useful for information, and for communication with policy makers.

The results were presented during the ReumaNet World Arthritis Day Symposium, in the presence of all stakeholders. The results have led to fruitful discussions.



Online self-management in Ireland

by Gráinne O'Leary, Head of Service Development, Arthritis Ireland



Over the past 10 years Arthritis Ireland has pioneered the development of services that enable people with arthritis to learn about self-management and put self-management tools into practice in their daily lives. Over the past 3 years we have embarked on a significant journey to bring these vital tools to even more people with arthritis through the development of an online education programme – [Living Well with Arthritis Online](#).

By the end of February 2017, over 1300 people had registered for the programme. What is clear so far is online education offers a unique learning opportunity to many people who would not otherwise attend a face to face class, at a reduced cost, with minimal on-going financial outlay.



This online course brings the essential tools and information of self-management directly to your computer and puts choice into your hands. In your own time and at your own pace, you can choose to become an efficient self-manager. The programme was researched, developed and implemented by Arthritis Ireland during 2014 and 2015. It is designed to 1) improve a person's understanding of their arthritis 2) introduce them to key self-management tools that can be used on a daily basis and 3) improve understanding of the various medications now available to manage arthritis. The programme is highly interactive and learning takes place through various video lessons with additional reading material available within each module.

When you log in online, you'll find tailored programmes for the six most common forms of arthritis. The various modules and videos teach you about your condition and the medications used to treat it, how to break the pain and fatigue cycle and self-management skills. And when you're finished, you can revisit it as often as you like. Arthritis Ireland's Living Well with Arthritis online course is available free of charge. If you would like to register log onto www.arthritisireland-education.com

In memory of Dora Papastavrou

Dora Papastavrou
*04.11.1983 – †12.03.2017



It is with deep sadness that EULAR PARE shares the loss of Dora Papastavrou, Member of the PARE Board, Greek representative to the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) and active member of our Greek EULAR member organisation E.L.E.A.N.A.

Her passion to advocate for young people was unstoppable. She was very active in the Young PARE Board and in many other activities. Her open, positive and courageous attitude won people's hearts. Her great support, contributions and her commitment to raise awareness for rheumatic and musculoskeletal diseases at national and European level were outstanding. Her wonderful smile, kind heart, enthusiasm and love for life will always be remembered.

Our condolences and thoughts go out to Dora's family – her father Anastasios Papastavrou and her sister Athina became dear friends and part of the PARE family over these past years – as well as to all her relatives and friends. Dora will be greatly missed among the EULAR PARE community and beyond.

We are so overwhelmingly sad to hear that the incredible Dora Papastavrou has passed away.

Having met Dora through the European League Against Rheumatism, it was instantly clear how kind and generous she was. Despite her own health challenges, she passionately worked to make the world a better place for everyone else.

She was taken too soon from our world, but her impact and words of wisdom, hope and happiness will stay with so many of us who had the privilege to work alongside her. She will never be forgotten.

"Cherish every moment and every person in your life, because you never know when it will be the last time you see someone."

Petra Balážová, on behalf of Young PARE



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



The Bone and Joint Decade
Promoting musculoskeletal health
Keep people moving

EULAR supports the BJD: www.boneandjointdecade.org